

Understanding End-of-Life in a Long-Term Care Home:
Perceptions of Bereaved Family Members

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Submitted in partial fulfillment of the requirements for the degree of
Master of Arts in Applied Health Sciences
(Leisure Studies)

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Abstract

Rather than a natural aspect of life, adherence to the medical model within long-term care (LTC) homes has framed death as something to be avoided and a failure of the system. The purpose of this phenomenological study was to contribute to the ongoing discussion in the literature regarding the experience of dying and death in a LTC home from the perspective of bereaved family members. Interviews were conducted with eight family members who had a relative die in a LTC home within the preceding 12 months. Interviews with participants focused on their experiences while their relative approached the end-of-life, at the time of death, and after their death. My findings resulted in the overall theme of *Respecting the Life and Death*. Within this theme, I found that *taking a compassionate approach to care; staff, families, and residents coming together for care; and the continuation of care* all supported residents on their end-of-life journey. The findings of this research call attention to the multifaceted nature of dying beyond physiological care and work to address ways to provide quality end-of life care.

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Chapter 1: Introduction

Growing concern with the quality of care in long-term care (LTC) homes has led to discussions within health-care communities regarding the need to critically evaluate current living conditions (Forbes-Thompson & Gessert, 2006; Kayser-Jones, 2002; Ragsdale & MacDougall, 2008; Stern, Miller, & Allen, 2010; Tuckett, 2007). In recent years, reductions in the number of staff within LTC homes have led to heavier workloads and greater time constraints, resulting in a tension in staff's ability to provide holistic aspects of care, such as emotional and social support (Armstrong & Armstrong, 2010; Campbell, 2013; Chroinin et al., 2011; Daly, 2013; Day, 2013; Sims-Gould et al., 2010; Tuckett, 2007). However, there has been a growing interest in making LTC homes more open environments that shift away from the institutional or medical ideal toward a social model of living.

Known generally as the culture change movement, initiatives have sought to “transform [the] institutional character [of LTC homes] into home and community” (Chapin, 2010, p 185). This shift, both in philosophy and practice, aims to make LTC homes more humanistic and person/resident-centred (Chapin, 2010; White-Chu, Graves, Godfrey, Bonner, & Sloane, 2009). Changes to the organizational structure, for example, include allowing frontline staff to be more involved in decision-making and reducing the top-down hierarchy that exists within LTC homes (Miller et al., 2010). Culture change practices also aim to address issues of LTC homes not being considered home-like environments. Flexibility in daily schedules, such as enabling residents to determine their own wake/sleep times, eating schedules, and menus also help to reinstate control and feelings of home (White-Chu et al., 2009). This culture change principle reflects the

hospice care principle, wherein residents are encouraged to act as if they were in their own homes (Moore, Carter, Hunt, & Sheikh, 2013).

Despite these recent efforts, LTC homes continue to be characterized by rigid routines designed to benefit staff and emphasize efficiency and incorporate a hierarchal structure, whereby frontline staff have limited control and an emphasis is placed on the medical and life sustaining needs of residents (Forbes-Thompson & Gessert, 2006; Stern et al., 2010). In this context, Forbes-Thompson and Gessert (2006) argue that “harm is systematically embedded in institutions where elders are stripped of personhood and meaning” (p. 246). Adherence to the medical paradigm ensures the inevitable focus on rehabilitation rather than consideration for quality end-of-life care (Reynolds, Henderson, Shulman, & Hanson, 2002). Nowhere is this tension between the care for the body and the person as a whole more evident than within end-of-life practices in LTC homes.

Death as a Medical Failure

Within LTC homes, the eventuality of death highlights the importance of emphasizing quality end-of-life care and helping people experience a good death, while being cautious against formulating a “right way to die” (Steinhauser & Clipp, 2000). The medical model has nonetheless framed death as something to be avoided and a failure of the system. Although aspects of medical care, such as pain and symptom management, are important to individuals facing the end of their lives (Heyland et al., 2010; Steinhauser & Clipp, 2000), modern medical technology has been acknowledged as sacrificing an individual’s independence and autonomy in order to maintain the physical body (Scarre, 2012). A medical framework distracts people from preparing for and accepting death, and dissuades the medical field from putting enough emphasis on their

role in supporting residents living in a LTC home to achieve a “good death” (Smith, 2000).

Shifts towards a more holistic, humanistic, and person-centred approach to care, which can be applied to care provided at the end-of-life, can be seen within the culture change movement (Chapin, 2010). The importance of this cultural shift is also reflected within governmental regulations, such as Ontario’s Long-Term Care Homes Act (2007), and the recommendations made by the parliamentary subcommittee report entitled *Quality End-of-Life Care: The Right of Every Canadian* (Carstairs & Beaudoin, 2000), which advocates for a national strategy to improve care for the dying and to reinforce the notion that quality end-of-life care is a right of all Canadians (Carstairs & Beaudoin, 2000).

Family Experiences within LTC homes

Research conducted with family of residents in LTC homes consistently highlights the importance of four holistic aspects of care, including: staff being there for residents and their families; positive and supportive staff attitudes (Munn & Zimmerman, 2006); staff making time for residents (Stajduhar et al., 2011; Wilson & Daley, 1999); and behaviours that reflect a deep personal connection to a resident and their family (Stajduhar et al., 2011). Family members also express a desire for consistent staffing to better ensure that residents have consistent staff working with them (Munn & Zimmerman, 2006); and to help families know who to talk to about a resident (Stajduhar et al., 2011).

An experience that allows families of residents to be present and involved in the dying process, including having a voice in the decision-making process, has been

recognized as important to the realization of a good death (Wilson & Daley, 1999).

Planning ahead for end-of-life care allows residents to have a say in what happens in the final chapter of their life and can help make potentially difficult decisions easier for family members and care staff (Scarre, 2012; Steihauser & Clipp, 2000). Through a better understanding of the factors that contribute to the experience of a “good death” in LTC homes, it is perhaps possible to help the LTC system overcome its current challenges in regards to quality end-of-life care.

Motivations for Conducting this Research

In 2008, both my paternal grandparents were diagnosed with Alzheimer’s disease. At the time of their diagnoses, neither had outlined their end-of-life plan. Given the importance of advanced care planning, my parents became tasked with blindly navigating the LTC system in hopes of stumbling across a LTC home that fit the distinct needs of my grandparents. Unsurprisingly, my grandparents were forced to move several times, within both the public and private spheres of LTC, before finding an appropriate facility and staff. Despite this extremely emotional and distressing experience, it was not until I took a directed reading course during my first year of graduate school that I began to think about these issues critically.

Through a therapeutic recreation lens, I was initially interested in understanding how to improve recreational opportunities and experiences within LTC homes. As I progressed through the directed reading course, I identified a trend in the research that suggested an overall poor quality of care within LTC homes, especially for individuals approaching the end-of-life. As I began to immerse myself in the literature, it became clear that structural issues within the LTC system extended beyond my initial focus of

exploring opportunities for recreation. Most notably, the literature highlighted significant structural barriers that limited the ability of staff to provide a high quality of care for individuals approaching the end-of-life (Katz, Sidell, & Komaromy, 2001). As I reflected on the experience of my grandparents, I began to ask myself: *What is a good death?*

Research Purpose and Questions

The purpose of this phenomenological study was to understand the experience of dying and death in a LTC home setting from the perspective of family who had a relative die “a good death” in a LTC home. This study was guided by the following two research questions:

1. What are the stories or memories held up as exemplars of a “good death” by relatives of a family member who died in a LTC home?
2. What does care that honours a “good death” look like?

To answer these questions, I sought to gather meaningful end-of-life stories from bereaved family members. I was most interested in learning how family members described their perceptions of a good death within LTC. It was my intention that this research highlight the successes and what is going well within an individual LTC home to help build a better LTC system in regards to end-of-life care (Preskill & Catsambas, 2006). That is to say, if I understood what factors contributed to a “good death,” perhaps I could contribute to the literature seeking to improve end-of-life care in LTC homes. What pivotal moments did family members recollect when describing how staff acted to support them and their relative during this time? What suggestions did bereaved family members have to improve end-of-life care within LTC settings?

In chapter two, I outline literature that supported my investigation of end-of-life care within LTC. In chapter three, I provide a description of the methodological framework that guided this research, and the methods that I used to answer the aforementioned research questions. The findings of this study contribute to the ongoing discussion within literature and LTC homes and help build an environment in which LTC homes become more affirming and compassionate places to die.

Chapter 2: Review of Literature

In this chapter, I provide an overview of the meaning and significance of LTC homes within society. I then discuss the tensions in health care as end-of-life care. Finally, I explore the concept of death and dying in LTC homes, how a good death is conceptualized in the literature and components that contribute to a good death including: (a) participation in the dying process, (b) advanced planning, and (c) strong relationships between staff, families, and residents.

The Meaning and Significance of LTC within Society

Through the provision of on-site resources, most LTC homes are able to meet the needs of residents without requiring them to leave the boundaries of the home. On-site resources in LTC homes can include: medical care, hair care services, dining services, and social/recreational activities. In this context, LTC homes are examples of what Erving Goffman (1961) describes as *total institutions*. Total institutions refer to facilities where, through the provision of on-site resources, the “inmate” becomes cut-off from the broader community. This closed, institutional approach to care has received considerable criticism from researchers for the detrimental consequences it has for residents including: reduced social contact with people in the community, increased idle time, less participation in activities, and loss of choice and increased dependency (Dupuis, Smale, & Wiersma, 2005).

The institutionalized space of LTC homes often creates environmental barriers for residents. The physical design of a space can support or impede a resident’s agency, independence, and mobility – concerns that remain relevant even as an individual approaches the end-of-life. Traditional LTC homes can be difficult for residents to

navigate, particularly for residents with limited mobility or those who use a wheelchair (Cooney, 2012). The limited communal space found within many LTC homes also restricts places where residents can sit and spend time in small groups or with their family and friends (Cooney, 2012), which can impact their ability to maintain these relationships as they approach the end-of-life.

The physical environment of LTC homes also creates issues around death and dying. For example, residents in LTC often share rooms. However, both staff and residents interviewed by Chroinin et al. (2011) highlight that privacy and peace should be provided to people who are dying and their families, and suggest a designated, quiet space for when someone is dying. Bereaved family members often support this idea, noting the value of peaceful, quiet, private, and clean environments (Stajduhar et al., 2011).

Residents' lack of perceived ownership of the space (Voelkl, Winkelhake, Jeffries, & Yoshioka, 2003) contributes to an ambiguity between public and private and can make it difficult for residents to know what is appropriate in the space or how to act (Hauge & Heggen, 2002). Adding to a resident's discomfort in these spaces is the lack of privacy for conversations. Despite staff and family members thinking that residents like to spend time in common spaces, residents often prefer to spend the majority of their time within their rooms. This may be because the lines of private and public are clearer within an individual's own room, but could also be because within their own room, they have to opportunity to exhibit control (Hauge & Heggen, 2002).

Person-centred care.

Person-centred care and its variants (e.g., resident-directed care, family-centred care, relationship-centred care) are part of the shift towards a more holistic approach to care and a humanistic view of residents (Hughes, Bamford, & May, 2008; Talerico, O'Brien, & Swafford, 2003). The following literature review focuses on person-centred care because the home where I conducted this research identifies with and follows person-centred practices.

Person-centred care is an approach in which care is guided by a resident's personal preferences and needs (Talerico et al., 2003). Person-centred care encourages the continuity of self throughout the transition to a LTC home and the time the person spends living there (Pirhonen & Pietilä, 2015). Components of person-centred care include: supporting autonomy, preferences, decision-making, quality of life and well-being as defined by the person receiving care, maintaining personhood, quality care, valuing relationships, supportive physical and organizational environments (Crandall et al., 2007; McCormack et al., 2012; Talerico et al., 2003). These aspects of person-centred care ensure that the person is at the heart of decision-making rather than supporting the norms and routines of the LTC home (McCormack et al., 2012).

LTC homes are able to promote person-centred care in many ways. Clarke, Hanson, and Ross (2003) suggest the use of biographical approaches as one way to "see the person" within LTC. Biographical approaches allow residents and their families to share their lives and build relationships with staff members, while simultaneously providing staff background information that can help them to improve the care they provide. Crandall et al. (2007) describe the experiences of homes implementing person-

centred care changes to food services and bathing routines and found that person-centred changes improved satisfaction, not only for residents, but also for families and staff members. Talerico et al. (2003) note that person-centred care can result in “better functional and behavioural outcomes for individuals and greater satisfaction with care” for all people involved in care – not just a resident (p. 13). It is important for staff at all levels to be on board and supportive of a shift towards person-centred care to ensure successful changes (Crandall et al., 2007). When frontline staff are empowered to make changes, and these changes are supported through education, policies, procedures and job descriptions, LTC homes set themselves up to provide benefits to people living in care, their families, and LTC home staff (Crandall et al., 2007).

Person-centred care has the potential to support residents and their families as a resident is approaching the end-of-life by providing them care that is tailored to their needs and wishes. When residents are known by staff and recognized as individuals, when timetables reflect the needs of residents and their families, and when people are given privacy, LTC homes are able to promote the continuity of self within the LTC home (Pirhonen & Pietilä, 2015).

Tensions in *Health Care as End-of-Life Care*

LTC homes “provide care and services to patients whose needs cannot be met in the community” through nursing care and support with activities of daily living (Brazil et al., 2006, p. 474). LTC homes are often conceptualized as one’s final home, a place where individuals go to die (Tuckett, 2007). Many residents experience loss of their home, independence, choice, dignity, privacy, and control over their daily routine (Forbes-Thompson & Gessert, 2006; Ragsdale & McDougall, 2008). This loss of control

for residents is compounded by LTC homes being conceived of as a “warehouse” to store people until death (Nolan, Grant, & Nolan, 1995); a “waiting house;” or a “pathway to death” (Tuckett, 2007).

A major structural barrier influencing the experience of death in LTC is the limits of staff. For instance, research by Tuckett (2007) declared nursing within LTC homes as “production line nursing” (p. 120). This analogy stems from the frustration of LTC nurses and carers who are often not allocated enough time to provide more than the basic needs of care before they must move on to the next resident. When a resident is dying, s/he creates a greater need for additional support staff, yet there is rarely an additional allocation of staff (Brazil et al., 2006; Katz et al., 2001). Staff in research by Chroinin et al. (2011) expressed concern that other duties prevented their ability to spend more time with dying residents. Sims-Gould et al. (2010) also acknowledge heavy staff workloads to be a barrier to optimal end-of-life care within LTC homes. Upon the death of a resident, staff members often experience a lack of support and are expected “to continue working despite their grief” (Chroinin et al., 2011, p. 58).

There is a lack of knowledge regarding how to have discussions about death with residents, including when it is appropriate to have these discussions (Kayser-Jones, 2002). Conversations about health status are often moved into the hallway to be had between staff and family, consciously excluding a resident (Tuckett, 2007). Even within review meetings with residents present, staff members have been reported to whisper amongst themselves and disregard the presence of a resident (Stajduhar et al., 2011). These findings reflect assumptions by LTC management and staff about the ability of residents to accept their own death, share their views on death, and desire to be included

in their own care decisions. These findings may also reveal a lack of understanding of the benefits of good communication, which can help to instil trust in the care team and decrease the anxiety and stress of family members (Stajduhar et al., 2011).

When residents bring up the subject of dying, they often encounter resistance or silence from staff members, demonstrating a communication pattern that is disrespectful and insensitive (Kayser-Jones, 2002). This lack of communication may also extend to treatment of family members, such as in a case reported by Forbes-Thompson and Gessert (2006), who described how staff did not acknowledge a family member who came to collect the personal belongings of a deceased resident. Moreover, in some LTC homes, residents are not given any notification when someone dies (Forbes-Thompson & Gessert, 2006). This is problematic, as concealing a death from the other residents “reflect[s] a belief that residents should be protected from death and illness” (Katz et al., 2001, p. 322).

These responses are a reflection of a LTC philosophy that residents fear death, however, current literature suggests that residents often consider death to be normal and in some cases, even welcome (Tan, O’Connor, Howard, Workman, & O’Connor, 2013). Whether residents prefer to be told when someone dies, and how residents feel about being put in their rooms with the door closed when the body is removed varies by each individual (Tan et al., 2013). A universal, medical approach to death and dying within LTC homes does not serve the individual needs and desires of residents and their families. This leads me to question what LTC homes can do to meet the needs of residents and their families in supporting residents to achieve a good death. To answer this question, we must first understand the history behind what constitutes a good death.

In the 1300s, the bubonic plague led the Catholic Church to publish the *Ars Moriendi*, which translates to “the art of dying” (Dugdale, 2010). In response to the overwhelming number of individuals dying, the Church decided to provide “advice to laypeople on procedures, protocols, and prayer for the dying” – as it was not always possible to have a priest at a person’s bedside upon their death (Dugdale, 2010, p. 23). The widespread crisis brought on by the bubonic plague led to the *Ars Moriendi* becoming popular outside of the Catholic Church. The non-denominational dissemination of the *Ars Moriendi* helped it to remain influential until the late nineteenth century. In the nineteenth century, “death became the enemy” as churches shifted their focus from dying well to living well, society became more secular, and medical advancements resulted in longer lives (Dugdale, 2010, p. 23). Western society once again became unprepared to deal with death, setting the stage for the contemporary struggle to achieve a good death within LTC homes.

Family roles in LTC homes.

The notion and myth, that families abandon their relatives in a LTC homes continues to plague ideas and public perceptions of LTC homes (Whitaker, 2009). Before their relatives move to a LTC home, many family members act as direct caregivers and experience a shift in roles and types of care that they engage in (Ryan & McKenna, 2014). No longer viewed as direct caregivers, discussions surrounding the roles that family members play within the LTC home setting often frame family members as ‘visitors’ (Gaugler, 2005).

As LTC homes strive to move away from their institutional roots, we can see ways in which family members are incorporated into the care system and do remain

involved in providing care (Whitaker, 2009). Many family members develop care routines and they describe their own involvement in terms of order and regularity (Ryan & McKenna, 2014; Whitaker, 2009). Visiting frequently enables family members to develop routines and be involved and integrated into the daily life of their loved one living in the LTC home (Baumbusch & Phinney, 2014; Ryan & McKenna, 2014). It is important to note, however, that family involvement is not summed up as simply being about providing direct care or how frequently they visit (Whitaker, 2009). Although these are aspects of family involvement, family involvement is truly a multidimensional construct that also encompasses other aspects of care such as advocacy and socio-emotional care (Gaugler, 2005).

One of the ways that family members can be involved is through direct care. Direct, hands-on care includes things like assisting with meals and activities of daily living, for example, toileting, bathing, dressing, and grooming (Whitaker, 2009; Williams, Zimmerman; & Williams, 2012). By serving as hands-on care providers, family members help to supplement the care work of paid staff (Baumbusch & Phinney, 2014).

Family members are resources for staff in other ways as well. Family members enable staff to understand the history, values, likes and dislikes of their relative (Boise & White, 2014). Family members are often able to identify health changes, sometimes even before staff can, because of their in-depth knowledge of their loved one's normal behaviour, appetite, and affect (Baumbusch & Phinney, 2014). Families also often get to know other residents in the home and can support staff in meeting their needs as well. Family members who help at meal times, for example, can help staff with food

preferences for other residents (Baumbusch & Phinney, 2014). Moreover, family members who are able to be more involved and visit the home often use their knowledge about other residents to act as a resource for other families who are not on-site as often (Baumbusch & Phinney, 2014).

Family members also take on important roles such as advocates for quality care within the LTC home (Boise & White, 2004). However, family members asserting themselves, and vocally advocating on behalf of their relative, or other people within the LTC home are not always well received by staff and administration (Baumbusch & Phinney, 2014). This is one of the many ways that we can look at the complexity and challenges of family involvement within this care setting. Baumbusch and Phinney (2014) note that there are boundaries to where and in what ways families are welcomed to be involved. A lack of structures and guidelines to support family involvement can create tension between staff within the home and families (Baumbusch & Phinney, 2014). Administrators identify the importance of families continuing to be involved (Baumbusch & Phinney, 2014). As such, it is important that homes foster that involvement by making positive use of families input, setting boundaries when needed, inviting families to be a part of care planning, care meetings, and problem solving, and providing education, training, and support so families can be meaningfully engaged with the care for their loved one (Ryan & McKenna, 2014).

Allowing and supporting family members to be involved within the LTC home is also very meaningful for family. For example, being able to share a meal together is about so much more than the food. Meals offer an opportunity for social and emotional care, for companionship, pleasure, and on a more practical level, provide family members

the opportunity to make sure their relative is eating (Whitaker, 2009). Family involvement is about companionship, and maintaining relationships and connections to the world outside of the LTC home (Boise & White, 2004; Whitaker, 2009). Family members carefully seek out roles for themselves within the home so that their presence at the facility can be purposeful (Baumbusch & Phinney, 2014). Families want to remain involved in the care for their loved one (Ryan & McKenna, 2014), whether out of love, responsibility, obligation, or repayment (Whitaker, 2009). Involvement in the LTC home also gives families the opportunity to maintain and guard the identity, dignity, and quality of life of their loved one (Gaugler, 2005; Whitaker, 2009). Relationships do not end with a move to LTC, and although relationships with family are often framed as beneficial for residents, they are beneficial for family members who visit as well (Whitaker, 2009).

Despite the advantages of family involvement to both family members and residents, there are additional challenges with involvement as a resident approaches his/her end-of-life. The move to LTC is often precipitated by decreasing health, increasing care needs, and overall poorer quality of life (Ryan & McKenna, 2014). Moving to a LTC home can provide care, security, community, and inclusion, which simultaneously contradicts the inevitable bodily decline, increased frailty, and, ultimately, death (Whitaker, 2009). Understanding these contradictions within the LTC home setting helps to elucidate part of why care within this setting is so challenging for family members. Some family members find it very challenging to engage with their relative, and family member's ability and desire to provide care may decrease as their relative ages and approaches the end-of-life (Whitaker, 2009).

Alternately, Williams et al. (2012) found there to be an increase in family involvement when an end-of-life period was recognized. This finding highlights the need for increased communication and for LTC home staff to help prepare families for their role during their loved one's end-of-life journey (Williams et al., 2012). Despite the many challenges of remaining involved within the LTC home setting, and being defenceless to an irreversible aging and dying process "family involvement is primarily about maintaining relations and accompanying each other until the very end" (Whitaker, 2009, p. 165). Similarly, Williams et al. (2012) found that family caregivers have a desire to be involved in end-of-life decision-making, and to be with their relative throughout their end-of-life journey; yet, there remains a paucity of research regarding family involvement during end-of-life and how/if family involvement changes.

Within the literature, it has been noted that families fear a "bad death" more than the experience of dying (Steinhauser & Clipp, 2000). Examples of a bad death include inadequate pain management, concern for future pain management, as well as perceiving cure-directed therapies to be too aggressive (Steinhauser & Clipp, 2000). This type of aggressive treatment, if considered inappropriate by family, can increase feelings of anxiety and neglect (Stajduhar et al., 2011). Although these particular concerns can be negated through medical care, I argue that addressing only physiological concerns is not enough to constitute a good death. Other, non-physiological, attributes that can result in a death being considered "bad" include: not being in accordance with family/resident wishes, being unprepared, disorganized care, family being burdened, dying alone, and the person being young (Kehl, 2006).

Staff in LTC.

Dominant discourses regarding the skill and training required to work at a LTC home may contribute to the lack of staff knowledge. On the surface, much of the social, emotion, and custodial care of LTC staff resembles the domestic work historically done by women within the home without any formal training (Armstrong, 2013). This “simple labour” is thought to require “the sort of soft skills that most women know how to do by virtue of being women” and is used to justify the low wages, less security, and less benefit coverage of staff, who are primarily women (Armstrong, 2013, p. 105). Because of the cultural devaluation of women and traditionally feminine characteristics, such as caring, staff of LTC homes are often overworked, underpaid, and improperly trained--contributing to a lack of staff knowledge.

Time constraints felt by staff members that limit staff-resident contact have also resulted in a lack of therapeutic activities within LTC homes. A person’s right to therapeutic activities, including those within the realm of therapeutic recreation, should not be diminished because an individual is approaching death (Hodges & Sorensen, 1998). Therapeutic recreation as a part of end-of-life care can help residents to manage their comfort, improve their mood, support relationships with families and friends, and distract residents from thoughts and medical procedures (Hodges & Sorensen, 1998). Nolan et al. (1995) and Pulsford (1997) note that LTC staff members, such as nurses, care assistants, and nursing assistants, feel that engaging residents in therapeutic activities is not their responsibility. As a result, what is offered in terms of activity is often dependent on the time constraints of staff members, how staff members regard the people they are working with, and the value staff place on therapeutic activities (Pulsford, 1997).

However, even when staff members are interested in providing activity, low staffing and being overworked often limits their ability/willingness to do so (Nolan et al., 1995).

A Good Death

Caring practices of LTC staff members are a main component of the quality of life for residents in LTC homes (Bradshaw, Playford, & Riazi, 2012). These caring practices include: meeting resident's needs without rushing, getting to know residents, and staff continuity. Family members of deceased residents have deemed caring behaviour of staff important in quality end-of-life care (Stajduhar et al., 2011; Wilson & Daley, 1999). Participants in research by Heyland et al. (2010) asserted the importance of compassion and support from doctors and nurses who were caring for them. These intangible forms of care suggest that staff play an important role in the lives of individuals approaching the end-of-life, well beyond meeting their medical needs and supporting them in activities of daily living.

Although the terms palliative care, hospice palliative care, and end-of-life care are often used interchangeably (Health Canada, 2009) for the purpose of this study, I will use the term end-of-life care. Hospice care has a distinct history of holistic care dating back to the 11th Century (Connor, 2009). When the contemporary hospice movement came to Canada, the term palliative was adopted to avoid confusion for French speaking Canadians (Connor, 2009). In addition to modifying the language of hospice, hospice in Canada was adapted to fit within the existing healthcare system resulting in the development of palliative care units within acute care hospitals rather than being separate from hospitals (Scott, 1981). Due, in part, to the location of palliative care units within acute care hospitals, palliative care has become closely associated with cancer, and

as such end-of-life care is a broader and more encompassing term that extends to include all end-of-life situations (Carstairs & Beaudoin, 2000).

The Canadian Hospice Palliative Care Association defines hospice and palliative care as that which “aims to relieve suffering and improve the quality of living and dying” (CHPCA, 2002, p. 17). Similarly, definitions of end-of-life care make reference to a variety of services offered to support the dying person and their families. These services provide pain management, relief from suffering, and bereavement support following the person’s death (Huskamp, Kaufmann, & Stevenson, 2012; Wilson et al., 2008). The provision of quality end-of-life care can support individuals approaching the end of their life in achieving a “good death.”

The concept of a “good death” encompasses many different components and has evolved over time (Kehl, 2006). Issues such as comfort, dignity, closure, tranquility, closure, preparation for death, time with family, and having wishes honoured can all contribute to a good death (Kehl, 2006; Munn et al., 2008; Munn & Zimmerman, 2006; Patrick, Engelberg, & Curtis, 2001). For this research, I focused on how issues surrounding advanced planning, strong relationships, and active decision-making all played an important role in receiving quality end-of-life care and achieving a good death. It is important to recognize that although we can look for commonalities between positive end-of-life experiences, “the concept of a good death is fluid and highly individual” (Kehl, 2006, p. 284). It is therefore important to take the time to understand the needs and wishes of individuals to understand how to best support them on their end-of-life journey.

Participating in the dying process.

Being able to participate in the dying process is important to family members and to the individual who is approaching end-of-life (Wilson & Daley, 1999). Involvement in this process includes understanding the dying process, being consulted about care, being involved in decision making, and for families, being present at the time of death (Stajduhar et al., 2011; Wilson & Daley, 1999). Having anticipatory conversations about these issues can help to ease anxiety and make decisions easier in times of high stress (Steinhauser & Clipp, 2000; Stajduhar et al., 2011).

Clear decision-making is made easier through communication with physicians. Being well informed by physicians empowers residents to be a part of the decision making process (Steinhauser & Clipp, 2000). The majority of bereaved family members in research conducted by Gallagher and Krawczyk (2013) felt the physicians listened to their concerns and that decisions were made with family input. However, these participants also reported wanting more information about a residents' condition and more information of what to expect when a person is dying. Addressing these concerns could help to improve the experiences for individuals approaching the end-of-life and their families. Closely interconnected with participation in the dying process, is the idea of advanced planning.

Advanced planning.

The decisions that need to be made in regards to end-of-life care, death, and the individuals' wishes and affairs that need to be addressed upon their death can be emotionally draining. As such, planning for death is an important process (Scarre, 2012). Watts (2012) understands a good death "as a reflexive, participative, relational, and

preparatory social process aimed toward some form of peaceful closure” (p. 22). In this context, the achievement of a good death requires deep understanding of the needs and wants of the dying person (Kelly, 2014).

Advanced care planning can make end-of-life care an easier process for an individual approaching the end-of-life, their family members, and the professionals providing care for them. An advanced care plan that clearly outlines a resident’s desires for their end-of-life care could help staff to remain focused on what is important to a resident with less influence of their own views on death. Advanced care planning can include advanced care directives, living wills, proxy designations, and values histories, where patients indicate their values and what gives their lives meaning so that staff can work and treat them in accordance with these values (Emanuel & Emanuel, 1998).

Heyland et al. (2010) found residents to be unsatisfied with the use of life sustaining technology towards the end-of-life. These technologies are the result of “our society’s tendency to deny death,” and focus group members in research by Steihauser and Clipp (2000) “demanded greater preparation for dying” in place of the denial of death (p. 829). Preparation allows residents and families’ voices to be heard in regards to whether they want these technologies to be used. Advanced care planning also includes clear communication about prognosis and psychological/spiritual preparation for death (Hanson, Henderson, & Menon, 2002).

Strong relationships.

Relationships remain important throughout one’s lifespan, even as an individual approaches the end-of-life. Munn et al. (2008) describe relationships as being instrumental in the delivery and receipt of end-of-life care. Personal, family-like bonds

have been identified by LTC staff as important in providing end-of-life care for residents (Munn et al., 2008; Sims-Gould et al., 2010). This is supported by family members of individuals who died while living in LTC, and who recount the importance of their relationships with LTC staff. Family members note that personal relationships – not just formal resident-staff and patient-doctor relationships, were valued by their deceased family member and helped them to feel affirmed as a whole person rather than as just as their illness or age (Steinhauser & Clipp, 2000). Heyland et al. (2010) also highlight doctors taking a personal interest in residents as one of the issues rated to have the highest importance by families and residents of LTC homes. The importance of staff-resident relationships again calls attention to the important roles staff play beyond medical care.

The structure of LTC homes contributes to the multifaceted and ambiguous relationships within this setting, as professional and personal relationships are intertwined (Munn et al., 2008). Beyond their duties for medical care and support with activities of daily living, LTC staff members also provide emotional and spiritual support to residents and their families, yet some families and residents find emotional support within LTC homes to be lacking and in need of improvement (Heyland et al., 2010). Being understaffed and overworked provides LTC staff with very limited opportunities to engage in the psychosocial or communicative aspects of care (Tuckett, 2007). Relationships within LTC vary in their degree of empathy, reciprocity, and trust (Munn et al., 2008). Family members do not equally reciprocate the empathy staff members feel towards residents and their families (Munn et al., 2008). This may be due to the fact that the bereaved family members had unmet needs, such as being given more information

about what to expect at the time of death (Gallagher & Krawczyk, 2013). Residents have also identified a desire to have more opportunities to contribute to the lives of others, whether through offering time, gifts, or knowledge (Steinhauser & Clipp, 2000).

In my view, residents in LTC homes stand to benefit from a continuing dialogue about how to improve end-of-life care. As such, I think it is important to integrate the voices of those directly involved in supporting those approaching the end-of-life in these conversations. By doing this, it is my hope that the suggested changes may accurately reflect the needs of dying residents. Although the literature on how to achieve a good death continues to grow, the medical model and the desire to extend the lifespan by “fixing” people still overshadows these ideals. In light of this literature review, it is clear that there is still work to be done to provide individuals with high quality end-of-life care and the opportunity for a good death within LTC homes.

This chapter illuminated some of the challenges that exist within current LTC homes. LTC homes continue to struggle to break free from their histories as total institutions to becoming more home-like and inclusive environments. As LTC homes integrate culture change practices, such as person-centred care and integrating families, they better position themselves to address the tensions that exist within this pluralistic space of home, health care, and end-of-life care. In this chapter, I discussed the challenges staff face to providing quality care. Despite the many challenges that exist, I suggest that a “good death” is possible within this setting, by ensuring that more than just the physical care needs of the dying person are met. In the following chapter, I outline the methods that I used to understand the experience of dying and death in a LTC home setting from the perspective of bereaved family members.

Chapter 3: Methods

The purpose of this phenomenological study was to understand the experience of dying and death in a LTC home setting from the perspective of family who had a relative die “a good death” in a LTC home. This study was guided by the following research questions:

1. What are the stories or memories held up as exemplars of a “good death” by relatives of a family member who died in a LTC home?
2. What does care that honours a “good death” look like?

In this chapter, I provide an overview of the study design and supporting phenomenological framework and influences of appreciative inquiry. The chapter will then outline the research process, including: site selection and sampling procedures; data collection and analysis; and ethical considerations, including: confidentiality, informed consent, and management of the data.

A qualitative research method was chosen for this study, as this form of research allows participants to provide in-depth explanations of their own experiences and express their own ideas. Providing participants the opportunity to give meaning to their own experience is one of the key characteristics of qualitative research (Creswell, 2007). Qualitative research also allows research to be inductive (Creswell, 2007). Inductive research, also known as bottom-up research, means that I moved from specific to general by discovering patterns, categories, and themes in the data (Patton, 2002). In this open-minded and context-sensitive approach, data are molded into codes, rather than fitting the data into a priori codes (Miles & Huberman, 1994). In my view, this made a qualitative

approach appropriate for this study, which is exploratory in nature and looked to establish themes and patterns rather than testing existing themes, patterns or a hypothesis.

Constructionism

Constructionism proposes that “truth, or meaning, comes into existence in and out of our engagement with the realities in our world” (Crotty, 2003, p. 8). In this way, constructionist researchers argue that meaning is not discovered or created by each individual, but is constructed (Caelli, 2000). Important to the meanings we create about phenomena, and how we create them, is the cultural embeddedness of phenomena (Daly, 2007). Situating my research within constructionism enabled me to work with bereaved family members to understand what stories and memories are held as exemplars of a good death by relatives and what care that honours a good death looks like and how these concepts are shaped by “the activity, language, and cultural symbols” of LTC (Daly, 2007, p. 32).

With this epistemological lens, researchers do not try to eliminate or act under the pretence that they have eliminated their substantial influence of all stages of the research process (Daly, 2007). In my research, I played a deliberate role in understanding and assigning meaning to the data as I was intentionally seeking information on a particular phenomenon within the “shared construction of knowledge that occurs between the researcher and participants” (Daly, 2007, p. 48). Constructionism suggests that what we focus on becomes our reality and that the language we use plays an important role in how our realities are shaped (Preskill & Catsambas, 2006). For the purpose of this study, it was important to be intentional and focus on the positive aspects of end-of-life care and

use language that reflected the strengths of the LTC home under investigation in order to work towards a future where these positive aspects of care happen more often.

Phenomenology.

Phenomenology originated as a philosophical approach that encouraged researchers to return to the ‘things themselves’ that are under investigation (Crotty, 2003). Edmund Husserl, credited as the founding father of phenomenology, criticized psychological researchers for attempting to use the methods of the natural sciences for human science (Lavery, 2003). Husserl noted that this approach created isolated responses born out of artificial situations that were not reflective of the life-world (Lavery, 2003). Through the use of phenomenology, Husserl looked to explore and create new meanings for everyday experiences (Daly, 2007; Lavery, 2003). This early use of phenomenology was based upon positivist ideals that suggested phenomena, and the life-world, could be explored in objective and unbiased ways (Dowling, 2007). Husserl encouraged putting aside existing understandings and assumptions about phenomena to examine the immediate experience with the phenomenon under study in order to uncover new meanings (Crotty, 2003). The act of ‘bracketing’ asked researchers to look at the life-world and experiences outside of, and separate from, culture (Caelli, 2000; Crotty, 2003). Husserl’s phenomenology has come to be known as transcendental phenomenology, which is a descriptive form of research (van Manen, 1997).

Martin Heidegger, Husserl’s successor at the University of Freiburg, expanded on and shifted the course of phenomenology. To understand how we are contextually situated in the world, Heidegger rejected bracketing and separating ourselves from the world (Lavery, 2003). For Heidegger, this meant being as aware of influencing

structures, such as culture and language, biases and assumptions, and accounting for these as much as possible in order to interpret and find meaning within the lived experience. Interpretation is one of the key differences between Husserl's phenomenology and the hermeneutical phenomenological work of Heidegger (van Manen, 1997). It is within Heidegger's work that we can see the appropriateness of using phenomenology within a constructionist epistemological lens, as Heidegger argued that we are both constructed by, and constructing the world around us (Lavery, 2003). With the recent publication of Heidegger's "black notebooks" there is much controversy surrounding his work and his legacy (Oltermann, 2014). Heidegger has been widely criticized for his anti-Semitic tendencies and for sympathising with the Nazi regime. Despite the controversy, Heidegger has played a major role in the development and growth of phenomenology.

Phenomenology has continued to develop over the past century. In North America, phenomenology has moved away from its philosophical roots and into a more practical application (Caelli, 2000; Lavery, 2003). In this sense, many phenomenological researchers now attempt "to understand the reality of their experiences *to the person* as they engage with the phenomenon" (Caelli, 2000, p. 370). In other words, I was interested in understanding the subjective experience of each of my participants. Hence, I was less concerned with traditional phenomenological pursuits into the pre-reflexive experience (i.e. bracketing), attempting to identify "truths" (i.e. objectivizing), or understanding the nature of the phenomenon itself.

It is important for this type of research to begin within the life-world. The life-world refers to the "lived world as experienced in everyday situations and relations" and

research in this area is guided by four existentials, lived space, lived body, lived time, and lived human relation (van Manen, 1997, p. 101). *Lived space* (spaciality) refers to the feeling of a space not the measurable physical aspects. In this research, lived space is relevant to the idea of ‘a sense of home’ as comfort, as it is or is not felt within a LTC home. Lived space offers the opportunity to explore the ways a space makes us feel, and what spaces we feel are best for the different experiences in our day-to-day lives (van Manen, 1997).

Lived body (corporeality) refers to the fact that we are always physically or bodily in the world. Our bodies offer us the ability to both reveal things and conceal things about ourselves at the same time (van Manen, 1997). As we age, our bodies change. For many people, health challenges and a need for greater support are precursors to a move to a LTC home. Within the LTC setting, individuals may be limited in their ability to reveal and conceal things about themselves because of both the presence of other people, and the reliance on other people for care and support. End-of-life is often accompanied with an even more drastic loss to the bodily abilities of an individual. Within this research, lived body refers to changes to an individual’s physical health status and how these bodily changes impact the ability to interact with others.

Lived time (temporality) refers to both subjective time and our “temporal way of being in the world” (van Manen, 1997, p. 104). Unlike clock or objective time, lived time shifts with whether we are enjoying ourselves or not. Temporality was relevant to the current study in regards to family members understandings whether they felt they had enough time with their loved one, whether the LTC home staff were able to spend enough time with their family member, and reflections on how their time was spent within the

LTC home. Lived time also encompasses the temporal dimensions of past, present, and future, and how each of these shapes us as we shaped them throughout the various stages of the lifespan (van Manen, 1997).

Finally, *lived other* (relationality) is the relations and connections to other people. Our first impressions and interactions with others are based in the lived body, but as we come to know someone, we are able to transcend the limits of the physical and experience “the other, the communal, the social for a sense of purpose in life, meaningfulness, grounds for living” (van Manen, 1997, p. 105). Connections between family members and residents, residents and staff, and staff and family members all play a role in shaping one’s end-of-life experience and enabling the achievement of a good death.

Appreciative inquiry.

This research was influenced by the foundational ideas of appreciative inquiry. Appreciative inquiry is a social constructionist idea that is typically used to support organizational change (MacCoy, 2014; Preskill & Catsambas, 2006; Whitney & Fredrickson, 2015; Whitney & Trosten-Bloom, 2010); it has also been used for community development, including healthcare communities (Whitney & Trosten-Bloom, 2010) and can therefore be appropriately applied to a LTC home. In contrast to deficit and problem-solving approaches where the focus is on what is not going well within an organization, appreciative inquiry is more closely aligned with a strengths-based approach (Preskill & Catsambas, 2006). Appreciative inquiry shifts conversations about change away from problems and what is wrong within an organization, suggesting that when you look for and at problems, you are more likely to find and create problems

(Preskill & Catsambas, 2006; Whitney & Fredrickson, 2015). Appreciative inquiry instead asks those involved to focus on what they want more of, focusing on past success to help find and create more success (Whitney & Fredrickson, 2015). Appreciative inquiry is aligned with my interest in a good death and goal to highlight how people come together to support dying residents and their family members within the LTC home setting. In the context of death and dying within LTC homes, I felt it was important to use appreciative inquiry to shift focus of end-of-life care from avoiding problems and stopping bad interventions to focus on the ideal of a good death (Emanuel & Emanuel, 1998).

Research Process

Site selection and sampling procedures.

In this research, I chose to contact potential participants through existing informal contacts at a LTC home, River Manor (a pseudonym). I began by contacting the administration of River Manor with an invitation to participate in my research (Appendix A). I provided members of the administration with a written overview of my research study, including the purpose, rationale, and scope of the study (e.g., number of participants and interview questions). Once access was granted (Appendix B), the administrator from River Manor contacted potential participants with information about the study and solicited interest in participation. Interested participants consented to have their information forwarded to me. I then contacted participants and informed them of what the study entailed and if agreeable to participating, I arranged a time to meet for the interview. Gaining entry to this study population required clearance through the Brock University Research Ethics Board, which I received prior to conducting my interviews.

I used purposive criterion sampling, which is used when the research question requires a researcher to find participants who meet certain criteria (Palys, 2008). In this case, I was interested in talking with participants who had had a relative at River Manor who experienced a good death. The advantage of this technique is that it ensured I found participants who were related to my research objectives (Palys, 2008). I had the opportunity to conduct six interviews - two of which involved two family members who contributed equally, resulting in 8 participants. To be eligible to participate in this study it was important that family members were actively involved enough in the end-of-life care and experiences of a resident in order to be able to comment on the overall experience and the quality of care (Stajduhar et al., 2011). Comprehension of English was also needed to participate. Of my participants, seven of the eight were women. Familial relationships included parent-child, sibling, and close family friend.

Data collection.

With this research, I sought the guidance and expertise of participants and heard their stories to understand the potential of improving end-of-life care in LTC homes. van Manen (1997) reasons that “we gather other people’s experiences because they allow us to become more experienced ourselves” (p. 62) so that we may become informed and better able to understand the deeper meaning and significance of the experience under investigation. In order to accomplish this, I conducted semi-structured interviews as a way to engage with and learn about the lived experience of family members who had a relative die within a LTC home.

According to Daly (2007), in-depth interviews are often used within phenomenological research “as a way to elicit detailed descriptions of this reality” (p.

98). Semi-structured interviews help maintain focus and can aid in analysis by ensuring some common domains across interviews while helping to maintain flexibility (Daly, 2007). The semi-structured format allowed for elaboration and variation in participant responses while gaining information on the topics of interest (Fontana & Frey, 2005). Within the semi-structured interview format, participants were empowered to help guide the conversation, allowing for issues or topics not previously identified or anticipated by a researcher to be addressed (Fontana & Frey, 2005).

Semi-structured interviews also allowed me as a researcher to probe specific topics and themes that emerged throughout the interview process. Although this format does have guiding questions to help guide the interview, it also allows space for silence, which as van Manen notes, “may be a more tactful way of prompting the other” (van Manen, 1997, p. 69). Embracing silence also helps to avoid the desire to fill space with meaningless chatter and questions that do not add to the depth or quality of the interview (van Manen, 1997).

Interviews were conducted face-to-face, primarily at participants’ homes, although one interview took place onsite at River Manor. To begin the interviews, I verbally reviewed the consent form with participants and allowed them time ask any questions, review, and complete the consent form (Appendix D). Interviews followed a conversational guide (Appendix E), and each interview lasted between 60-90 minutes. Interviews were audio recorded, allowing me to be fully attentive throughout the interview process (Daly, 2007). Recording the interviews also allowed me the opportunity to re-examine what was said and transcribe the interview verbatim for analysis. Each participant was interviewed once, and the interview explored how

participants described the death of their relative, what practices within LTC they felt contributed to their experience, and how they, as family members, perceived their role within a good death.

Analysis.

To begin the process of data analysis, I began with immersion in the data (Green et al. 2007). This included listening to the interviews multiple times and transcribing the interviews verbatim. Transcribing the interviews acted as a form of data preparation and put the data into a form for analysis (Sandelowski, 1995). I then read and re-read these transcripts in order to “see and appreciate the subjective experience of the participant” (Daly, 2007, p. 219). To explore and isolate *essences* of the phenomenon, I used a detailed line-by-line coding approach (van Manen, 1997). This inductive approach does not work from existing criteria where a researcher looks for certain words or phrases, but instead focuses on the discovery of what a phenomenon means rooted in the experience (van Manen, 1997). Although van Manen (1997) refers to this process as line-by-line, it is important to recognize the arbitrary nature of where a line begins and ends, and instead use meaningful units of data – regardless if these constitute more or less than a line (Chenail, 2012). This process of coding the data breaks the data down into units and applies descriptive labels.

From these *essences* (i.e. codes), I developed *categories*. Creating categories is the process of examining how codes can be linked together (Green et al., 2007). This part of the analysis remained descriptive. It is important within phenomenology to go beyond the mere description of the lived-experience to interpretation of the data (van Manen, 1997). The initial categories were created for each interview and then compared across

interviews. Some initial categories were merged together and new categories were created as I began the process of comparing the experiences of different participants. From the descriptive role of essences and categories, I then shifted my analysis to generating overarching *themes*. Themes are a higher order grouping of categories (Ryan & Bernard, 2003). Finally, themes attempt to offer an explanation or interpretation of the phenomenon under investigation and link the data to broader research (Green et al., 2007).

After completing the data analysis, I arranged to send each participant a summary of the analysis as an opportunity to engage them as co-researchers and reflect on themes that emerged from the interview (van Manen, 1997). This summary reminded participants of the purpose of the study, described the findings and thanked the interviewees for participating in the research. This allowed me as the researcher, to have the opportunity to share with participants the findings from the stages of data analysis. The purpose of sharing these findings was to give participants the opportunity to share their thoughts on whether they thought the findings are representative of their experiences, and to provide any other information or details they would like to add. Participants' comments were addressed, and included into the final findings.

Ethical Considerations

Due to the sensitive nature of the research topic, it was important that as a researcher I remained aware and considered potential harm due to participation. Research was conducted in accordance with the Tri-Council Policy as mandated by the Brock University Research Ethics Board. Approval was gained through the Brock University's Research Ethics Board prior to the beginning of this study.

Informed and voluntary consent.

Patton (2002) suggests that the way in which you chose to study the world determines what you will learn about it. I acknowledge the sensitive nature of the topic I chose to explore, and as such wanted to be sure I remained conscientious of this throughout my research process. Participants were first asked if they wanted to participate in the study through a letter of information (see Appendix B). The letter of information outlined the purpose of the study, what would be involved in participating, potential benefits and risks, researcher contact information, rights to withdraw, assurances with regards to publication of statements, and contact information for the Brock Research Ethics Board. Participants were asked to give written informed consent (see Appendix C) if they wished to participate in the study, and if they consented to the interview being audio recorded.

Should a participant have become upset after or during the discussions surrounding their family member's death within the LTC setting, I was prepared to provide him/her with a list of possible support services to access free of charge. Participants were also informed of their right to withdraw from the study prior to commencement of the interview, and would have been reminded of this right should they have seemed upset, or asked if they would like to take a break. Additionally, as a researcher, I was not immune to the emotional impact of these discussions. As such, I was prepared to use debriefs with my supervisor as a way to unpack and reflect on my emotions and thoughts about the interviews. I also used a reflective journal to help me engage in self-reflexivity and to negotiate this complex issue.

Confidentiality.

Every effort was made to ensure participants' confidentiality. Participant names and name of the LTC home did not appear on the transcribed data, and was instead identified using codes – with only the researcher having the information that matches the codes with the participant's names. Materials were stored in a password-protected file on my computer to ensure materials were stored in a secure manner in accordance with the Brock University Research Ethics Board's guidelines for confidentiality. Finally, because it is my duty as a researcher to protect the confidentiality of participants, I have left participant quotes unidentified, rather than using pseudonyms, as a way to protect participant confidentiality. I have also chosen to include only a vague description of the home, primarily using participants' language because of the risk to confidentiality.

Chapter 4: Findings

This chapter will outline the findings of my analysis. My analysis resulted in the theme of *Respecting Life and Death*. I begin this chapter by introducing River Manor and using the voices of participants to help me describe the way this home is viewed in the community and what their relative's rooms were like. Then I outline the theme of *Respecting Life and Death*, and then describe the three main sub-themes, which are a *compassionate approach to care, coming together to care, and the language of a good death*.

River Manor

River Manor is a mid-sized home in Ontario. River Manor has a good reputation within the community. This is corroborated by participants' stories. One participant described River Manor as a model LTC home, noting "*it's sort of like Zehrs stores has a location and it has everything they want to demonstrate to all future people coming around and River Manor is the equivalent of that in the long-term-care homes.*" This idea of River Manor being an exemplar home is echoed by participants having only wanted their loved one to move into this particular home. Another participant, for example, described how she and her siblings "*went back [to CCAC] and said the only place we want him in is River Manor, no other home on the list.*" Similarly, a participant had concerns that her mother would have to move to a home that was not River Manor saying:

We thought she was going to end up in [other home] I just wasn't going to let her. I said to my husband, well she couldn't stay home, the doctor wouldn't let her be home, I said she's not going to [other home]. If I have to she's coming home with me till River Manor becomes available, but that didn't happen, so I was really happy with that.

Other people also recommended River Manor to participants, and its reputation has spread through word-of-mouth. When looking for a home for their father, one participant and her family were also influenced by the reputation of River Manor and by witnessing firsthand the ways in which they live up to that reputation.

Yup, and other people who have their parents here or spouses or whatever yeah, it's just through word of mouth and just even walking in this place you can just see, if you spend a day here... watching what people are doing, they really care. They really make the staff aware that they are caring for the elderly not you know, they're not machines.

The location of River Manor was also important to family member participants. Most participants in this study live close to River Manor and mentioned how short the drive was to be able to go and visit. One participant mentioned only living a five-minute drive from River Manor, and another participant lived only fifteen minutes away. The convenience of living close to River Manor was described by a participant because it was easier to make frequent shorter visits, unlike the previous home their loved one had lived in, noting that *“because it was sort of a half hour drive it wasn't easy to pop in and you know have a fifteen-minute conversation or an hour coffee and then you know, take off.”* The closeness also made it easier to stay connected and involved, as one participant mentioned only having a seven-minute drive made it easy for both her and her husband to be involved at the home and to bring their family member home. This ability to stay connected was also important to another participant, and the closeness to River Manor was a part of why this home was the right choice for her father:

We didn't want him being out of the area where most of his family was. Most of his family and friends and extended family are all in [local region], so for CCAC to say well you know we don't have bed there we'll have to put him up in [another town] that would have been the worst thing for my dad, because he wouldn't have

had the communication with his own family like we couldn't have gone up there every day.

Their closeness to the home continued to be advantageous to families, and the relative they were visiting, as their relative approached the end-of-life and families were present at the home more frequently. One participant described how “*distance was on our side for sure*” as it allowed her and her husband to go home and shower and do whatever they needed without it taking away from their time with their family member.

When participants were asked to describe the physical space of River Manor they had positive things to say. When describing her sister’s room and the space of River Manor, one participant said:

Well hers was beautiful and you see like I say we toured enough when I go down south I actually visit some people in homes down there and I think they’re pretty nice. River Manor was nicer than anything. It was beautiful and it was even better than the retirement home where we had her in too. So no it was great, and the common areas, the beautiful brightness of River Manor was what really appealed to me when my husband and I went on a tour last fall because we had to put her name on the list so we put it at the top of the list.

One participant mentioned the nice big window in her mother’s room, and mentioned, “*The space was fine. The rooms are a decent size. They're not huge, but they're not really cramped either, and you don't have anyone in like a bed next to you either.*” As her mother’s end-of-life neared, the closeness of the space was comforting to families as one participant said: “*During that time you want to be close to her. There is no sense being at the other end of a big room. I had more space than I needed.*” In addition to looking nice, the rooms had everything that residents needed.

River Manor maintained a sense of being home for many family members living there, as one participant said, “*it was hers, it was her room, you know, and it was all her*

stuff, you know, it felt like she was home.” This idea of River Manor feeling homelike for participant’s family members relates to van Manen’s ideas of lived space. For this participant, the language of calling River Manor home was something that originated with her mother:

And then when I would actually take mom out, I'd bring her home, or take her somewhere she'd always say can you take me home now? So that really made me feel better you know that she felt that was where home was and where she wanted to be.

For some participants, being in the same room until death was important because it was their space and where they were most comfortable and because being in the same space meant they would have staff they knew working with them. The physical space of River Manor provided a comfortable environment for residents and their families throughout their time at River Manor. Not only was the home aesthetically pleasing to family members, the ability to personalize the space contributed to a sense of ownership, and of River Manor being home.

Respecting Life and Death

Given that many people move to LTC homes, as they get older and their health declines, the experience of living and dying at River Manor is accepted, comfortable, and natural. Families appreciate the willingness of staff to learn from families and gain significant knowledge of their relative in a short amount of time. Residents are supported from the time they move into the home until their deaths. River Manor meet residents’ physical and medical needs, but they also work to engage them in meaningful activities as well. River Manor provides social events to allow residents the opportunity to engage with one another and members of the community. As residents’ health declines and they enter end-of-life, family members feel comforted by the knowledge that staff care deeply

about their relative and guide families through end-of-life care. Staff continue to meet the physical needs of residents providing them comfort and relief from pain as they embark on their end-of-life journey. This upfront, honest, and accepting approach to end-of-life care calls attention to some of the ways in which River Manor respects people in living well within LTC and in dying well. Respecting Life and Death has four sub-themes of *compassionate approach to care, coming together to care, continuation of care and the language of a good death.*

Compassionate approach to care.

This category explores the care families and residents received throughout their time at River Manor. *Compassionate approach to care* includes: (a) caring attributes of staff, (b) guiding families through end-of-life, (c) personalizing care, and (d) symbols of bereavement. The compassionate care that family members and residents receive at River Manor is central to their overall experience within the home. These subcategories reflect the ways in which care was demonstrated to families within the LTC home throughout a resident's time there, including their end-of-life time. This category speaks to van Manen's existential of lived human relation because the compassionate approach to care taken by staff exemplifies the relationships and connections developed between staff at River Manor, families, and residents.

Caring attributes of staff.

Family members I spoke with in this study had many positive things to say about staff at River Manor. Staff were described as being kind, caring, happy, very friendly, very positive, understanding, and helpful. When I asked about staff, one participant noted: "*I will say, amazing staff, in their support and attitude while she is healthy, if you*

will, and their support and attitude to the family while she is slipping away.

Unbelievable.” Another participant, who had struggled to find an appropriate home for her sister with the proper supports, described the difference she felt when her sister moved into River Manor:

Because it was the difference of night and day, having had this agonizing thirty days to go in and be welcomed at River Manor they cared about me, and they explained what was going on with [sister’s name]. They said what support they offered and most of all you know assured me that she would be safe and comfortable, but beyond that she would be stimulated to the points where she still had the reasoning and appreciation.

Yet another participant, who said of staff, *“I don’t think they could have done more to please me,”* corroborated this appreciation for staff at River Manor. When asked about staff, a fourth participant said:

Yeah, again family never saw any problems, and coming from my dad as well, he always had positive things to say, never a negative thing. Because I would go in and ask him, I said, you know ‘how was your food today’, you know? ‘How did you get along with this nurse’? He always said ‘oh they’re all really good’.

The comment from this participant suggests that not only were family members satisfied with the care their relative received but so were residents of the home themselves. Other participants’ comments extend this idea of being happy with staff and the care they provide, to the way staff acted like family towards residents:

If I probably could have thought of something they could have done, I would have suggested it, quite honestly, because I am a doer and I would... But they do have a lot of really great programs, and a lot of great volunteers and lot of great staff. I really can’t think of anything more they can do to be the replacement family cause from my view they mostly do have to be the replacement family.

Finally, family member’s positive perspectives of staff were in part due to staff being welcoming and inviting towards families:

They were very supportive and very open and there was never- I never felt at any time from any staff that I ought not to be there, or they'd prefer me to be somewhere else... It was just the total opposite it was what more could they do.

Participants used positive language to describe staff at River Manor. Family members recognized a high level of care from staff who treated participant's relatives like family and were welcoming and open to families, which was part of the compassionate approach to care taken at River Manor.

Guiding family through end-of-life.

As relatives reached end-of-life stages, River Manor was able to help prepare families and offer them guidance through their loved one's end-of-life:

It's not just hocus-pocus; here is what's happening and why, and why we're saying what we're saying. Yeah, it's nice to be treated that way. None of this, 'well, we're professionals and we know, just trust us that's what's happening.' It was just so super.

Staff were considerate and upfront with family members about the fact that their relative would die soon; although they were not always explicit in the language they used. One participant, as an example, noted:

She sort of explained, sometimes, what does happen, like how the body shuts down, and yeah, but she never really would say either then you know your father is dying, you know, she just explained sort of the process and that everybody is different in how long they take to die, but yeah, they were very responsive.

Family members appreciated being informed of what was happening and what staff was looking for:

One incident...that just sticks in my mind was one night I was there, and a nurse came on duty and said, 'we're getting close, and these are the signs that we look for, this is what's happening here, and what that means, and this is the physiology here,' and, it's just telling us this, that was good.

A participant, who had a challenging experience at her mother's end-of-life, found the support and guidance provided by River Manor to be soothing while going through the end-of-life process with her sister:

But these other trained people, who have the hospice training, they understand how to bring that person through that journey, so they knew the signs, when things got toward the end with my parents I was given no understanding, I was so upset. I kept wanting somebody to fix them, even though they couldn't, here at River Manor they help you understand what's shutting down, and what cannot be done at this point and how you should accept and they provide so much counselling.

This participant was also impressed with the booklet the home provided her with. This booklet, combined with the guidance of staff, helped her to be present with her sister throughout her entire end-of-life journey:

Just flip in and see the headlines for each of the categories there, cause it gives you the stages and that is the most helpful booklet for me... Cause they went through the breathing changes at the end, and they told you that at this point, well it sounds terrible, they're no longer aware and in mother's case... it would have been helpful because they probably would have said well it's due to whatever's going on in there and she's not feeling pain and that would have really... but I didn't even hold her hand at the end and that gave me guilt for a long time because I was so frightened I sort of picked up a newspaper to read just so I would take my thoughts off of what I was hearing coming, so there again I was able to overcome those feelings because I had the guidance of the staff.

Providing this guidance allowed families to be prepared throughout the stages of dying, and helped ensure they had time and space to say their goodbyes. One participant mentioned how with his mother-in-law they “*were invited in to be there and say goodbyes and I love you’s and things like that.*” Another participant talked about how even staff took time to say goodbyes to her loved one:

But people I think obviously had time to say their goodbyes and to be present and... this one gal who was going off shift she did say that, you know, she might not, she wasn't going to be in the next day and that she'd be back the following day and she said I don't know if I'll see [relatives name] again.

The guidance that staff at River Manor provided families helped guide them through this challenging time and honour the person by respecting their individuality and honouring them throughout the final phase of their life.

Personalizing care.

Staff showed a compassionate approach to care by personalizing the care they provided. Families liked that staff working with their loved one were consistent:

I really liked that the staff is consistent. So you always saw staff you knew, and that makes such a difference to the resident because they know that face, you know they might not know who that person is but they know that face, and I've found that every time I went in it was always the people I knew working, you know which made it so much easier.

Another participant corroborated this sentiment; noting the advantage of how long her loved one had lived at River Manor:

The nice thing about her having been in that unit for two years was that there was a consistent group of personal support workers and as well as nurses and who knew her and knew her well.

Families appreciated that staff took the time to get to know their loved one and took time to treat them as an individual and attend to their specific needs:

And they really were intuitive to him as well and his needs and his character of how to handle him, he got a little bit stubborn sometimes. [They were] very good at that, yeah, knowing how to handle his needs, not having a just one specific way of doing things for everybody, they look at each individual and look at the characters and they knew him to a tee. It was all very good that way.

One participant remarked on the way staff took time to get to know her sister as a person. For instance, when her sister moved into the home, staff asked the participant to provide background information, including things like what her sister's childhood was like. Staff also demonstrated an appreciation for who residents were as individuals:

For all her, I mean, you know stubbornness at times and things like that I would say you know they also enjoyed her sense of humour and her independence and the strong woman that she was, and feisty, and determined.

Staff also showed care and attention to details that helped honour the person at the time of living in River Manor, and the things that had always been important to him/her:

They always made her even right to the end, mom always liked to have jewellery, she didn't have real jewellery you know she'd have costume jewellery, but right to the very end they dressed her, they put her jewellery on, they made sure her hair was done, because that's who she was, and you know it wasn't like oh well she's dying were not going to worry about it. You know, they'd have fun picking out clothes from the closet... right to the very end they were so caring.

One participant shared with me how her mother had cats her entire life and that while living in River Manor she continued to have cats – some imaginary and one was a stuffed animal. Staff did not fail to notice the importance of this stuffed cat to her mother:

And other thing with, with the staff and I guess it would be the PSWs when they would go to roll mom over so she wouldn't get bed sores, they would do it, the two of them would do it and do it as gently as they could. Then they'd take the kitten and just tuck it in mom's arms again.

Family members valued the care that and effort that was put into looking after their loved one. For example, one participant observed, *“the love they showed in the time [sister's name] was there was just remarkable. Every one of them knew her well.”* Finally, staff members play different roles that enable them to personalize the care they provide and meet the needs of residents:

Yeah, but here they also have like each individual like their dieticians, their physios, their recreation workers, they're all very experienced, they all have their role to play and they all did it very well, you know, whatever my dad needed or wanted, they would send in whoever was required to do the job.

Meaningful engagement in life. Staff at River Manor were also able to develop relationships and personalize care for residents through the activities they offered. River Manor offers a wide variety of activities for residents to be involved in, and made an effort to support residents in being involved in activities as they encountered changes to their health and abilities:

They used to when they could they'd take her for walks, they'd put her on a bike and the back like somebody rides it and then she's in the back and they'd tour her around the place and take her out, towards the end it was it didn't really make sense to do much with her because she really she wasn't getting anything out of it, but they still tried you know different things. They'd bring different games, just moving you know the balls along this thing or whatever. But she'd just sit there with she couldn't connect it to do it so... yeah she was kept busy enough. And I mean if you've got your mind and your able to do it they've got so much going on.

This participant went on to describe some of the many activities River Manor offers to its residents, and noted that there is always something to do with all the great programming they put on. Many participants commented on how their family members enjoyed participating in the activities:

When I first came home in April she was still enjoying her surroundings, she liked her, she always liked the exercises, she liked the structure, and so as my kids said they'd go to see her and it was hard to find time between her breakfast and her lunch because there would be exercises in here, and their drives... they had long drives and they'd get there and she'd have 15 minutes and then she'd be watching your watch because all of the sudden well it's going to be exercise time. So, yeah, she loved all of the activities, all the way up to the end.

At the same time, many participants noted a decline in their loved ones ability or willingness to continue to participate in activities as marking the beginning of a decline towards end-of-life stages:

She participated in activities on going until she absolutely couldn't, you know would totally nod off and her just not being able to get out of bed, so, for a long period of time, through her stages of un-wellness, she still very much wanted to go out on a drive, or go out on a bicycle, and, go to things if she could, even though she may fall asleep in it or have to leave early, she would still want to go and that was facilitated which was great, facilitated on the part of the staff at the Manor.

The attention to detail extended to the people the home brought in for special events. One participant recalled taking photos for River Manor at a Christmas party and his impression of the musicians they brought in:

I don't know where they would find the musicians to come in, but they played well to that audience, and went around afterwards and just interacted with them.

Providing a wide range of activities, and taking the time to support residents in being involved in these activities was meaningful for family members. Although when participants reached end-of-life status they had stopped participating, families valued the care shown and the relationships developed throughout the time their relative was living at River Manor.

Symbols of bereavement.

After her father died, one participant noticed an ornament on the door of his room – a marker to other people that that person had died. For this family member, this tiny gesture was symbolic of the attention to detail and care her father had received throughout his time at River Manor:

Just little things like that just really make, the people are really concerned and care for their client- for the residents here. They really go the extra mile with the little touches, like I said with the [ornament] on the door, that little booklet at the end, you know, no they really try to think of everything here.

A [symbol] at her mother's place setting stood out in a similar way for another participant:

They have a thing that they do there that really was unbelievable for three days, at moms table setting where she always sat there was nothing there but they put a [symbol], for three days in a row. And when I went there that day I looked right at moms, where she used to sit, and it's empty of course, and so I asked them and they said oh we do that. I thought that just was like, that is, you know, you can tell they cared about that person, it wasn't just a matter of oh she's gone now who are we going to put in there, no for three days it was still her seat and it had a [symbol] on it.

When you enter River Manor there is also a table where they put pictures of people from the home that have died, and a book people can sign and leave a note for family:

They do a 'we remember' picture if you do want to sign condolences, or they have like a table where they probably put a picture, and they would be very sensitive to like if we put a picture of mother in the newspaper for her obituary they would pick that same picture because they would think that you like that picture, so then that's the picture that we'll put on the table to say we remember [mother's name]. But I think that it helped me so that when I would come and see her and I would walk past this room and say hi to [a resident], and all the sudden [that resident] isn't in that room and I'm thinking so what? Did [he] die? Which sounds again horribly brutal the way I just said that, but you know, they could have been moved to another wing.

Family members were also appreciative of the gesture of the book with notes from staff and other residents:

They do have the book that they have people sign, so we did get that. That was nice, because then, a lot of the staff had stuff written in there, and a few of the residents, so that was nice.

The final symbolic gesture, though certainly more overt, was the memorial service at River Manor. Every few months, River Manor hosts a memorial service for the people who had recently died. Again, it was clear that this was more or less meaningful for different participants. For one participant, it represented how skilled River Manor is not only at taking care of residents who live there, but also their families, saying “*they just understood what to do with the families.*”

Coming together to care.

This category explores the ways in which River Manor worked with families and supported relationships throughout a resident’s time at River Manor and throughout their end-of-life. This category includes: (a) open communication with family, (b) families as partners in care, and (c) being guided by the voice of the dying resident. River Manor works to foster a philosophy of partnerships between families, residents, and staff at the home, which contributes to the quality of care that people experience there. Again, the connection between the category and van Manen’s existential of relationality can be seen. The relationships and inclusion of families in the care of their loved one demonstrates River Manor’s openness to creating an open, meaningful, and communal space.

Open communication with family.

Participants thought that staff at River Manor had strong communication skills and maintained contact with family members well. Family members were able to approach staff to ask questions about their loved one. One participant reflected on checking in with staff when she arrived at the home, and how they would take the time to let her know what was going on with her mother’s care. This participant also talked about

being impressed with the quickness with which staff would contact her if something happened:

Mom had a couple of falls, it's within minutes that I got a phone call, saying "Don't panic, everything's fine, your mom's fine but she did have a fall" and they'll tell me what they're doing and I, so of course the first time I ran there because I thought you know I've got to go and check this out but the nurse stayed there and she took her blood pressure every 15 minutes for an hour just to make sure all that was done, I mean they check everything you know, I was, I was totally amazed that they just all stepped into you know?

Another participant commented on how staff kept records of various things related to a resident's care, making it easy for her to find out information about her father. When staff did not readily know the answer to a question, they were quick to get back to families:

If I had any concerns they would, if they didn't know the answer, they would say you know we're gonna get right back to you, and within that day they would talk to the head nurse and then they'd get back to me and we'd talk or whatever.

Family members also reflected on how staff kept them informed of changes that occurred with their relative's health or behaviour. Several participants discussed noticing changes to their relative's activity levels and the ways in which staff kept families informed of these changes:

So when things started to go that he wasn't going into the gardens and into the ch-like going to church services they made us aware of these changes as well, so when that started we knew that things were slowly changing. They made us aware of all of his changes, yeah.

Families appreciated being kept up-to-date on what was going on with their relative. And, as one participant commented, this included hearing positive news as well: *"yeah, and that was one thing to when there was something to celebrate as well as be concerned about we'd get a call. Apologies, but you, you know, with that we'd like to know. Yes! Thank you."*

Families as partners in care.

The open communication between the home and family members as well as the welcoming attitude of staff as discussed under the positive attributes of staff allowed families to be partners in the care of their loved one. Family members clearly have a much longer history and more in-depth knowledge of their loved ones and were therefore able to provide staff with insights about their relative. One way that this partnership in care manifested was that staff included families in care planning, such as through the annual family conference:

Because of the annual conference I mean they can ask some of those questions to say has your parent prearranged a funeral? Do you know who that decision maker is when it gets to that difficult time when we need to make difficult... In my case, I think they were pretty clear, they knew who it was.

Staff were also open to hearing a family's feedback and working together to develop solutions:

Yeah I think that for the most part it was fairly, fairly good in terms of the contact and I kind of just clearly communicated about wanting to be informed and updated when there was any significant changes or you know, and sometimes needed to say well can we not look at if this is, if she's - not it wasn't really agitation, but if she's in pain can we not look at how we either introducing something new, what's working, or if we're increasing.

As well, family members were able to use their own expertise to support their relative and provide care:

He wanted to continue walking and we always encouraged that too, cause that keeps the mobility up, and I have one brother and a sister who are [allied health professionals], so they would come in and treat him every once and awhile and encourage him to walk, and like I said before every time we came here we always tried to get him up and go for a walk.

The roles that family members played in their relative's care varied between participants and the stages of their life. One participant reflected on the common goals of staff and families, those being to support a resident and provide the best care possible, but also recognized that their duties were different. Some family members did participate in care that would otherwise be under the duties of staff:

But generally there was an appreciation this way [pointing to herself]. Thank you for changing your mothers pad, thank you for putting clean clothes - or her clean clothes, thank you for taking her up to the dining room. So, if I said, don't worry about it, I'll put her to bed, obviously that gave that person 15-20 minutes, or better.

Although staff appreciated extra support from families in this way, they were also supportive to the needs of family members and did not pressure them to participate in any form of care. When reflecting on her own feelings of burnout, staff reassured one participant that they could manage her sisters' care:

They always assured me to when I sensed them you know like I'm begging them for some guidance because I don't think I can hang on much longer, they would say to me, well we're fine looking after her, we'll look after her you don't need to come, so that was comforting.

Some family members saw their role with their loved ones care, specifically at end-of-life, to be more about emotional support, or as one participant put it *"just in bearing witness. I don't think we had a role to play as such, to be there that was the role."* She went on to express how they *"didn't have to do a song and dance or anything,"* again suggesting that there was no pressure or obligation to be involved in care in any one specific way.

One role that many participants reflected on was that of an advocate for their relative:

I think the only role was as an advocate for my mom, you know making sure things were done and but I really didn't have to worry about it you know? It yeah, just being there and you know being kept up to date as to what's happening and her condition... no just to make sure that things were done.

Because, in part, of the closeness of families to River Manor, many participants were able to visit regularly. One participant tried to visit daily, another was able to visit a couple times a week herself, but because of her large family, her father had someone visiting every day. One participant was able to visit almost daily, as was her sister who would often take her lunch to River Manor to spend time with their mother. Yet another participant went to visit her mother 2-3 times a week. Living slightly outside of the community where River Manor is located, one pair of participants tried to visit once a week. Being able to visit regularly enabled families to feel connected to their family member:

Again because I was close I found for me stopping regularly gave me the best, so sometimes I would stop on my way home from work. If I didn't do that I pretty much always stopped in every night after supper. I would say once a day on the weekend... not that it was a big huge visit, or that I did anything wonderful, but it was just a little bit of just an observation, a little bit of a connection.

Visits looked different for the different families, and varied depending on their loved one's health. Some visits included going home with family members, especially in times when the relative was healthy:

We were able to bring her home lots to have meals at home, to come and sit by the pool, to, you know to do things and do things in the community, and take her places and take her on drives all the time, and she could come home and have extended you know visits too, I think she stayed over at Christmas and things like that usually at the beginning.

But, one pair of participants talked about how their visits with their loved one became shorter as her health declined and she was no longer able to manage spending the entire afternoon with members of her family. They also would take their family member for shorter drives, or shorter visits home, to allow her to continue to do the things that she enjoyed, like getting an ice cream with family, but at more at more manageable level. Another participant also made an effort to take her mother out of River Manor to do special things that she enjoyed, like going to the horse races, and her mother would happily tell everyone at River Manor when she was going and if she won.

The typical family visit was generally less exciting. Families would often share a meal or a cup of coffee with their loved one. They would visit either in the loved one's room, the gardens (in nice weather), or other common spaces of the home. Two participants both spoke about being able to bring their dogs to River Manor, and how it meant a lot to both their mothers. The other residents also liked to see their dogs:

Yeah, grandma just loved having her [the dog] come to visit. So it didn't matter all the rooms, and you got to know some of the other residents, [another resident's name] who in his wheel- his little power scooter would always want to see the dog, a bunch of people. So yeah, it was usually good.

Visiting and doing things with their family member were opportunities for families to contribute to their loved one's care in a social and emotional way. By being supportive of families' involvement, at whatever level they were comfortable with, River Manor and families were able to work together to provide high quality care for residents.

Being guided by the voice of the dying resident.

Throughout the care of their relative at River Manor and their health changes and challenges, family members worked to make choices and advocate for the type of care

their relative would want. For some families, it was easier to keep their loved one involved in decision-making. One participant used an iPad to have conversations with her close family friend about what she wanted in terms of care. Although the participant was the final decision-maker she appreciated being able to get her close family friends input on issues related to her own care:

She was very clear with what she thought... and so that in terms of her take on things made it much easier, and I think, and knowing that I didn't find the decision difficult or having to do that because she was clear in her wishes and it wasn't different from what I thought probably would be the most sensible choice anyways and so that made it fairly, fairly easy.

One participant was also fortunate that her mother was open about her wishes, and was able to use conversations she had had with her mother to guide the care that she was given throughout her end-of-life journey:

Mom said, you know if I'm dying just let me go, don't, don't rush me to the hospital, I don't want surgery, I don't want any of those things that are going to take me awhile to recuperate from, so when I'm going just let me go, just, you know, I don't want to be in pain, give me what I need for pain, but other than that that's it. And that's exactly what we did, yeah.

Another participant reflected on how it was “nice” to be able to have conversations with her mother about what she wanted while she was able to have those discussions, which took some of the pressure off when they reached the “critical state:”

So I liked that, but you know you would have to go like do you want to be resuscitated, do you want just comfort, do you want to donate your organs, all those, it's kind of nice when you can have those conversations when you're not in the critical state, it's like you don't want to go on planning a funeral the minute after somebody has died. It's nicer when you can plan the funeral when they're alive... when it's not in the critical state, that all makes this end-of-life, happy death possible.

But as one participant highlighted, even if her father had not been open to sharing what he wanted for end-of-life care, it was her job to make decisions based on what her father would want, not based on what she wanted. This participant said, *“well yeah, and I mean that has to be, I mean if you're thinking what is the best thing in terms of what you want that's not, that's not the way you should be thinking.”* She worked hard to keep her father's thoughts in her decisions and was able to keep him involved in care conversations:

It's not about me; it's about what is the most comfortable for him and how he would want his end of the life to be. Yeah. Where he wants to be at the end of his life, so a little prodding, and cueing, sort of helped a little bit you know in how you say things to him, yeah. He was pretty reasonable and acceptable with most of the decisions that we made for him.

However, for some families, their relative was less able or less willing to be involved in care conversations. One participant, who had played a role in her sister's care throughout most of her life, had always been the final decision-maker. For this participant, keeping her sister involved in care decisions was less about asking her directly and having her involved in that way, and more about being sure that she understood the choices:

If I explained to her that this was in her best interest, and I always explained to her fully because she kept her mind was as sharp as it ever was right through to her final day, I knew that she could understand and she trusted me and I would always do what was in her best interest.

One participant and her husband faced resistance from her mother when it came to discussing what she would like in terms of care. Her mother was unwilling to talk about death or anything related to death. For this husband and wife, then, honouring her mother's wishes required a little more guess work. They used the participants' father, as a

guide for what her mother wanted, although even he was not very open to discussing his end-of-life wishes:

Yeah, so we knew he wanted to be buried, don't think he wanted cremation, so we were able to get some information. You even mention that to my mother, she did not even want to talk about any sort of care, nothing. Just shut down completely. My father would talk about some stuff, not a lot but some.

Family members I spoke with had different experiences in terms of their loved one's willingness to discuss their end-of-life wishes, but throughout all their stories we can see an effort to keep the interests of residents at the heart of all decisions made in an effort to honour who that person was.

Continuation of care.

As residents of River Manor approached the end of their lives, staff extended the care they offered to include families. The care they received and being prepared for their loved one's death helped families to accept death and the accompanying grief. Finally, after a resident had died, River Manor once again continued to show care to towards family members, and offering any needed support. Continuation of care has three sub-themes: families care for at end-of-life, accepting grief, and care after the death of a loved one.

Families cared for at end-of-life.

As River Manor helped to guide residents and their families through a resident's end-of-life journey, some aspects of care they provided changed. Staff continued to meet the needs of residents and extended their caring more towards families:

I would say to some point that they were both is there anything we can do for your mother, so they were first of all concerned about her needs but at some point they would say also, if you are going to stay you know there's a room where you

can stay, or if you want something to eat we can bring you a drink or bring you a sandwich, a chair, you know, those kinds of things. So, I would say that they were attentive not just to her needs but to our family's needs without over doing it.

Families were offered food, coffee/tea, a room where they could stay if they needed, and extra chairs for people to sit. Participants also spoke of staff bringing in a CD player and being able to play music that was familiar to their loved one. As one participant put it, *“but they couldn't have been better they just knew exactly how much support and when.”*

These extra supports helped families continue to feel welcomed to be with their loved one:

They just allowed me to be there and when [sister's name] began to fail a little more and a little more I just increased the time. I was there every day... and they didn't mind they made sure I was welcome in the morning they showed me where to find the coffee myself if nobody else asked me, if I wanted some you know, it was just it couldn't have been a better reception.

Staff continued to support families in making choices and providing them appropriate information without pressuring them to make a particular choice. One participant also commented on the balanced compassion they offered, showing concern for her and her mother's well-being without being over the top.

This sub-category clearly demonstrates the importance of van Manen's ideas of relationality within River Manor and the end-of-life journey. The care families received during their loved one's end-of-life was merely an extension of the care they had received throughout their time living at River Manor.

Accepting grief.

I asked participants if they thought having had a “good death” or a more positive end-of-life experience helped with their grief. For some participants, a good death

certainly did not eliminate grieving, however, some commented on having fewer regrets. As one participant said, *“maybe a little less grieving and regrets. But I don't think it helped the grieving process just the terrifying time of the slow death.”* This idea of having fewer regrets was common amongst participants. For instance, someone also commented on having no regrets about her mother’s care or end-of-life journey saying, *“Probably, because it was positive, I'm not trying to replay it and thinking I wish it would have or I wish I could have done it again, so I don't have regrets.”*

Knowing that their loved one had received great care supported participants in experiencing fewer regrets, and also helped them through their grieving process:

It [a good death] just made it easier it made it, you know there's a lot of times I wish I could go there because it was so part of my life now I've got all this extra time but it definitely helped me to know that she was cared for if I hadn't and that she died comfortable and she died surrounded by people that cared about her, definitely makes it a lot better, definitely makes grieving easier, doesn't take it away.

For one pair of participants, knowing that their family member had been well cared for, and that she would not have been happy to continue with her declining health and inability to do the things she loved helped them to manage their own grief:

...And knowing that she would not have wanted to continue, like she had made it very clear she would not have wanted to, would not have been happy that that was the way things were like in terms of if she'd continued living like that.

One participant echoed this sentiment in her member-check email, when she remarked on how after her stroke her sister was severely limited in all the activities that she loved most and that this helped her to accept her sister’s death.

For participants in this study, the death of their loved one was not a surprise. For many participants, their relative had gone through various stages of un-wellness and

previous times when they thought they might die. This seemed to contribute in a different way for the way that families were prepared for their loved one's death. Family members also expressed an acceptance that it was their relative's time, and in one participant's case there was also a sense of giving her mother permission to let go:

The next time I talked to her, I called everyday then. ...And I could tell the way she was breathing that there was just no way, so I just said mom, "it's okay, we're going to miss you but it's time for you to go, you know, you can go, and you know I'll see you again someday," and she died that morning. So, I felt better, I think she waited for me to tell her it's okay to go. So she did.

Another participant was very open in discussing how she knew and was able to accept that her mother was ready to die:

But it got more where she would be probably saying yeah, I want to go and be with [husband's name], which is my dad. She would say, yeah I'm ready. If you want to have the minister come I could go at any time... I'm tired, I'm done, I'm not having fun anymore, and those are my words not hers. But that was the message loud and clear, I can't see, I can't walk, I can't do all those 101 things that I'd love to be doing that I used to do and I can't do them anymore. And I'm tired, and I'm ready, and I'm done.

Grief, for these participants, was mediated by knowing their loved ones had lived long, happy lives, and that in the end, they had care and guidance to lead them through their final journey. Family members also saw grief in staff at River Manor. As one participant stated:

That there would be enough response from the staff to make you realize that it wasn't just a loss to the family, but that they felt a loss of a resident, and that it's a member of their family when they're at work, so it felt like a shared loss. It didn't feel like oh good, now we've got an open room for somebody else, like it didn't feel like an assembly line. Which it could, but it didn't. It also felt you know I mean people have deaths when they're young, and when they're in accidents and when they've got fatal diseases, it never felt like well she was old she should die. There was none of that yucky type of feeling. It felt valued; it felt like quality care up until the end and even at the end that quality still would be there.

Sharing in families' loss helped them know that their loved one had been cared for, and to honour the life that they had lived.

All participants of this study were prepared for their loved one's death, and that also impacted their grieving:

With my dad, we were sort of prepared for it, all the little subtle innuendos from everybody sort of prepared your mind for this is not- this is the end. So yeah, when it actually happened of course you're still very upset at the time, but I felt much more prepared for this one. And like I said with my mother, but that was a different circumstance, not prepared, the grieving process was very heavy after the fact and I said that before that I found this death a lot easier to deal with because it was more prepared or expected and dealt with.

Anyways, so again we're all as expected obviously we're not shocked, we're not heartbroken, but yes we are sad because we're going to miss her so when you love somebody you're going to miss them, so that's all good.

Because of the gradual health declines, grief, for many of participants did not start at the actual time of death, as one participant said: *"and because of the time leading up to her dying too, I mean you're grieving through that period of time."* For another participant, her grieving process had been extended over many years:

I probably grieved my mother ever since she had encephalitis, when she stopped being this super hero wonder woman who was doing everything to all the sudden she couldn't put an x on a piece of paper.

The idea of accepting grief reflects not only van Manen's existential of relationality as the care and relationships between staff and residents supported families in feeling confident in the care their loved one had received at River Manor throughout their end-of-life journey, but also the idea of lived time. Being able to accept that their loved one was ready to die and being prepared for their death highlights one of the ways that temporality can be seen in the end-of-life of residents living in LTC.

Care after the death of a loved one.

The way the home used various symbols to represent and inform people that someone had died is only one way in which the care provided by River Manor continued after someone's death. One participant spoke of the care shown toward her immediately after her sister died:

They still showed concern for me and it was, they wanted to be sure I was alright and you know it was 11 o'clock at night when she died and to you know just check with me make sure I was alright to get out to my car and head home, oh there's a lot of care.

Another participant reflected on how her family was given time and space after her father's death, and how staff were sensitive in how they approached family:

No, they gave us time, and then I think [staff member] came in and she stated her sadness and gave us her sympathy and condolences and we were all hugging and crying, she was, she was very, very, very nice and you know she said you have such a wonderful family and your dad was very lucky to have you all, and you know to be there for him, and then you know she would just say if there is anything we can do let us know, so we stayed for a little bit.

As they had been throughout their loved one's care, family members were still invited to be in the space:

We were just invited, you know, obviously to stay there was nothing that there wasn't any rush to you know to leave the room or anything like that and I mean we could have stayed actually longer than what we did but you know she -the spirit had gone, and so we had time and everybody had time, and we had time together.

However, most participants also remembered the 24-hour timeline they were given to have their loved one's room emptied out. For some families, this was slightly more challenging, given that they did not have much family in the area to come and help. Although 24-hours did not seem like very much time, many participants also expressed

their understanding as to why there was such a short timeline, as can be seen in this exchange between two participants:

Participant 1: Did I go back that evening for the stuff?

Participant 2: I think the next day.

Participant 1: The next day, you had 24 hours. No it was that evening, I went back that evening, um, cleared out her room, and her room was closed you know, and there was the cart, because I had phoned to say I'm coming, because you have 24 hours to clear it out. So that's the only thing I wish it was a little longer time, but they've gotta...

Participant 2: There are a lot of people waiting to get in, and not a lot of space

Participant 1: Yes, so...

Participant 2: The practicality we understand.

Another participant, who unlike the previous two participants had plenty of family available to help clean out the room, reflected on her experience of cleaning out her father's room, saying:

Yeah. So yeah, on the day of going through his things, yeah, there might have been some tears, you know, looking at pictures or something like that but all in all no it was pretty good. I think we were given 24 hours, but she said if you needed a bit longer we could request it, but because there's such a high waiting list here, so 24 hours is a bit short notice for some people maybe cause they were just having to deal with a death, like we had two or three days to prepare for it, you know where maybe if somebody died suddenly and then all of the sudden in 24 hours they have to move everything I would think that might be a little bit hard.

Once again, having known that the person was dying made this process easier for this participant, who not only thought it would have been more challenging if it had been sudden, but also reflected on how having a big family to help with the burden of cleaning out the room was an advantage. For another participant, cleaning out her mother's room was a time for staff to come and chat with her and share memories about her mother:

When I went in there to pack it up when I got back, I had a hard time packing it up because they were all in there, they all came in, they all came one-by-one and they came and they'd say so how are you doing? You know, and oh they'd talk

about mom, you know, and all the funny things she'd said, you know and how she'd made them laugh. And it made that go so fast you know because I swear I had 15 different people just come in, just to say you know your mom was great, you know we're gonna miss her.

This response once again highlights the care staff at River Manor provide for families of residents, as well as speaks to how they will also miss the deceased person. The care and respect shown by staff at River Manor helped to honour the life of the person who had died, and even when asking families to have the room cleared out quickly, they worked to support and honour the people yet to reside at River Manor:

Well I know when we were how glad we were when we got the call to say there is a room for [sister's name] and that's just it, I just translated that to the fact that I can understand them having to clean the room do the things that they have to do and soon as that.

Another participant echoed these sentiments, recognizing the attention that staff paid to her and her mother and also the need face the reality that she no longer needed the space:

You could look at it as a bit abrupt and cold, but again it's business, and it's not even just business, there are people who need that room, people who are waiting for that room. It's, it's a crime, it's like having a homeless person who could be in a home. I mean it's just wrong on every level to deny that.

The language of a good death.

When reading the literature of death, dying, and end-of-life care within LTC homes I found the language of a “good death” particularly interesting. I continue to struggle with whether this is the best language we can use to describe positive end-of-life experiences. I chose to use my interviews as an opportunity to explore this language with people who had witnessed and been a part of the experience of a “good death.” For the most part, family members did not like the language of a “good death.” One participant,

for example, said, *“I don't like the term good death, I think there should be a different word with a good death. What's good about death? I just think that's an inappropriate word.”* Another participant expressed similar discomfort with the language saying:

Yeah, I would say the quality was there for end-of-life, good death, I have a problem with. Good death is not an external thing to my mind, it's the circumstances, was mom's good? Yeah, she wasn't there when it happened.

Despite not liking the term good death, participants reflected on understanding what that language was trying to encapsulate. Family members suggested other language they thought might be more appropriate, such as *“peaceful death,” “comfortable death,” “relaxed death,”* and *“happy death”*. One participant took the time in her member-check email to suggest the language “natural death,” saying that in her definition *“A natural death in my definition of such is one that is not prolonged unnaturally. The patient is given ‘comfort measures only’ but recognition is that the patient does not stand a chance of regaining a full life.”* Another participant, who in part was uncomfortable with the language of a good death because it polarized the idea of dying so if someone did not have a good death they would have had a bad death, also struggled with finding appropriate language:

Yeah, I guess no, because what do you say it could be peaceful but then it could be unpeaceful right? And so I guess to have and maybe some people would want it if it's a continuum from bad to good where might they say there experience was, right? Like if it was a line or a continuum because I guess it could be just really bad and you know a really good, and I would say that our experience was really good.

I also shared with participants my preference for the language “quality end-of-life care” which I think encompasses the aspects of what makes up a good death, but with less

problematic language. After sharing my language preference with one participant, she said:

I like your version better, really. Good death to me is not, because I know even though I wasn't there I know how mom struggled while she was dying, like you know, can't breathe and pulling on her breath and all that. So good death doesn't sound right to me. But I guess what they're meaning is not necessarily the death itself it's the before.

When I reflected on how saying quality end-of-life care covers the experience surrounding the dying experience this participant said, *"Yeah, for that I would say that it was a good death, yeah, definitely."* One pair discussed that the experience was good for them, but that they have no way to know if it was good for their family member, as one quipped, *"probably wasn't her first choice."* Similarly, another participant felt her experience was good, but that her sister had a "bad death" because she did not accept she was dying and struggled through her end-of-life journey.

When asked what she felt was important to achieving a good death, one participant commented on the importance of the guidance and support she received from River Manor:

Just having the support of professionals around whether it's volunteer professional volunteers, but people who understand the stages... So that's all, just to have the guidance of people who can share with you experiences.

Another participant expanded on this sentiment, noting that the supports family and their relative needed were in place:

She had good symptom...like pain management, she [had] somebody with her, yeah so there was time for her to do those things that or to have people that were around her and people to come visit and the care... I think it was good it was in a place that she knew and was comfortable and she had people that cared for her and yeah there was really good symptom management, they looked at like saying

okay well like why are we doing all these other meds, like, so there was “well what is actually needed here in terms of support?”

One participant highlighted some of the things she thought played a role in her mother having a “happy death,” saying:

But let's talk about this happy death. Yes, couldn't have been better. You know and I have to qualify that by saying some of that is good luck. Some of it is good planning, some of it's good support from the staff.

Two participants reflected on the importance of their loved one's comfort, though despite the comforts and supports they both noted that it was not an easy experience, saying:

Death is never easy, no, but if people make it easy for you and give you the comfort measures so you can deal with it it's much nicer. We were very glad because we did have a decision to make whether to keep him here or to send him and transfer him to the hospital and we said we want to keep him here and that was the best decision we made. Cause they were just wonderful here. Yeah.

Similarly, another participant was pleased with River Manor and was able to feel good that that is where her mother spent her final years and moments:

So that all kind of helps that then when you replay it back that you can say yeah, I can feel good about that, I certainly, I do feel good about the Manor, I totally do, I feel good that as good as quality of life could have been, that there's not anything that I can think that as an institution that they could have done, or should have done, and as staff that they could have done or should have done. I would say they looked at the needs of the person and what was happening and they just adjusted to kind of go with the flow.

Of all the stories and ideas of what family members thought made up and contributed to a “good death,” I was particularly struck by the analogy that one participant shared with me:

I think sometimes the language that we use in terms of like you know the focus of like living, right? Or like if you look at it like a plane and so you work to keep the airplane going but that death is really the landing of the plane. And so the plane

was landed well, there wasn't a lot of turbulence there wasn't a lot of right? It wasn't you know a frightening experience right? And so I think because there was more focus put on doing that well so I think the death was done well in terms of the care and support that she had.

Well we don't tend to focus very much on landing the plane, we focus on keeping the plane going and getting the plane up right and so but I think that there when there's effort and thought put into the landing the ending and getting everybody off the plane well who was there supporting that landing then I think it's yeah, it's good.

Stories such as this allowed me to better understand the factors that appear to contribute to a “good death.” Indeed, being able to be present with someone as they approaching end-of-life, having space and time for saying goodbyes, having guidance from staff, maintaining comfort, being prepared, it all works together to “land the plane” and honour the person through their final journey.

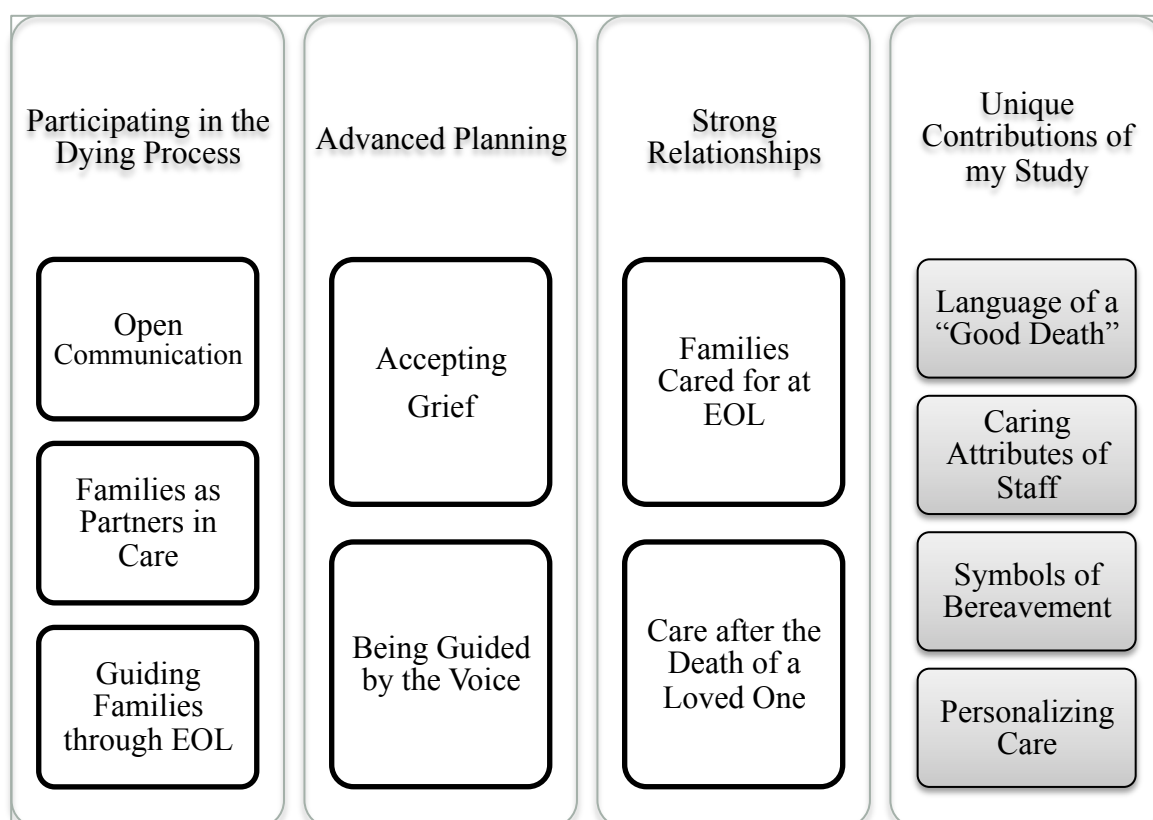
Chapter 5: Discussion and Implications

Overwhelmed by the number of negative stories in the literature about end-of-life care within LTC homes, I began this research hoping to shift the focus from what is not working in LTC to what is working. I wanted to understand the experience of dying and death in a LTC home setting from the perspective of family who had a relative die “a good death” in a LTC home. Through semi-structured interviews, I was able to learn about the experience of end-of-life care in a LTC home from the perspective of eight family members. This research highlights the contributions of River Manor to advocate for positive end-of-life care by supporting individuals and their families across the end-of-life journey. Through an exploration of bereaved family member’s experiences of having a loved one die in a LTC home, this research supports the understanding that LTC homes can provide quality and supportive end-of-life care to individuals who are dying and their families.

In this chapter, I bring in end-of-life and LTC literature once again to situate my findings. For the purposes of this discussion chapter, I will speak to a number of concepts that I believe act as the organizational foundation for a “good death” in LTC -- applying hospice care best practices to LTC home living, advocating for an environment in which dying and death is not feared, but considered a natural aspect of life, and practicing care beyond the dying person. The final concept I will address speaks to family members’ recollections of the death of their relative, and is something that continually struck me as I moved through data collection and analysis. With the organizational foundation for a “good death” established (above concepts), family members can draw on memories of the

relational care received by staff during their experiences in LTC. I also explore implications for this research, and suggest directions for future research.

To bring this discussion I have included the following chart to demonstrate how my findings are situated in the literature, using the same headings as my literature review, and to demonstrate the aspects of this study that are unique. “Good death” is language that is commonly used within this research, but as I found in this study, it was not language that resonated with people who have been through this experience. The caring attributes of staff, symbols of bereavement, and personalizing care were all unique to this study, although an argument could be made that these aspects of care are manifestations of strong relationships within River Manor.



Care at River Manor is Reminiscent of Hospice Care

River Manor's approach to end-of-life care is in line with the philosophy of hospice care. Consistent with my overall theme of *respecting the life and death*, hospice frames death as a "natural continuation of the life cycle" (Moore et al., 2013, p. 155). Indeed, hospice care "aims to relieve suffering and improve the quality of living and dying" (Canadian Hospice Palliative Care Association, 2002, p. 17). Given the data gathered, it appears that River Manor is part of a broader movement towards more holistic and supportive care within the LTC system. Rather than conceptualize death as a failure, staff and management at River Manor saw death as natural process and sought to support the individual and their families throughout the end-of-life journey.

In this research, participants called attention to some of the ways in which staff and management at River Manor operate beyond the traditional medical model approach to health and the bureaucratic challenges that exist within this setting. Within the medical model, health is "synonymous with 'cured' and care has become an intervention towards that end," (Day, 2013, p. 25). According to Day (2013), this singular biomedical conceptualization can have particularly troubling implications for older adults within LTC homes. The various forms of care within River Manor, such as their compassionate approach to care and continuation of care, demonstrate the possibilities and limitations of expanding ideas of health and caring beyond "curing" within the LTC system. At River Manor, staff are able to negotiate barriers created by the bureaucratic nature of this setting. Although they likely still feel the pressures of time and heavy workloads that are so common within LTC home settings, staff at River Manor are able to provide families

with a level of care that makes them feel as though their loved one is part of the family at River Manor.

Within Western society, technological and medical advancements enable people to live longer, but this often comes at the “high costs of the subject’s independence and autonomy” (Scarre, 2012, p. 1082). Hospice enables an individual who is dying to “retain as far as possible the authorship of the final chapter of her life” (Scarre, 2012, p. 1082). As such, individuals receiving hospice care are supported by the hospice system to maintain agency, autonomy, and control in regards to treatment (Connor, 2009; Raudonis & Acton, 1997; Scarre, 2012). At River Manor, personhood was not lost when the health of residents began to deteriorate and they became more dependent on care. Staff worked together with families, and continued to be guided by the wishes of a dying resident, even after s/he was no longer able to directly express those wishes. Schwartz, Mazor, Rogers, Ma, and Reed (2003) reported that the majority of their participants considered following the wishes of the dying person to be essential to having a good death. By being conscientious of the desires of residents’ family, staff members were able to support residents in having control throughout the final stages of their lives.

Hospice also allows people time to prepare for death (Connor, 2009); and again, preparation for death was important to family members I interviewed. As noted by Mathie et al. (2012), “dying is not an unexpected outcome following a move into a care home, although often not acknowledged at the time of entry” (p. 734). As such, there is a certain level of preparedness for death, which comes with age, health challenges, and setting, which created the sense that these deaths were appropriate (Kehl, 2006). For all participants in this research, their family member had faced health challenges and gradual

health declines that helped families prepare for their death. As well, most family members were able to articulate that their loved one who lived at River Manor was accepting of their own death, which aligns with Kehl (2006) who proposes that recognition of impending death, through awareness and acceptance, is an important attribute of a good death. Family members also spoke of having the opportunity to be with their relative to say goodbye, thus providing a sense of closure (Kehl, 2006). River Manor also helped families prepare for their relative's end-of-life by ensuring they knew that their death was close and guiding families through their relatives' end-of-life by providing information and understanding of what was happening.

Hospice care offers people the opportunity to prepare for death -- allowing them to reflect on their lived experiences (Connor, 2009). Hence, there is a need to comfort and support both the physical body and the mind. In a discussion about the possibility of achieving a "good death," Scarre (2012) describes dying as both "an existential predicament as well as a physiological condition" (p. 1082). In this research, participants did not speak to the ways in which River Manor supported individuals approaching the end-of-life or their families in finding meaning in death. As much of hospice care is directed towards people with life-threatening illness, perhaps then, it makes sense that within this setting, they intentionally make space for meaning-making. Within LTC care, despite the realities of this being a common place for death to occur, and for many, death is an expected outcome of moving into LTC (Munn et al., 2008), we do not necessarily see the intentionality in preparing people for death in an existential way. This highlights one area that perhaps LTC homes can learn from the existing practices of hospice to grow their own abilities to support residents.

Kayser-Jones (2002) expresses concerns about staff members' lack of knowledge on how to have discussions about death with residents. It is important that staff receive training on conversations about death with both residents and their families. Personal and professional experiences with death and end-of-life care have been associated with positive attitudes about dying and the supporting roles physicians can play in end-of-life care, knowledge about death, and lower reports of negative emotional responses to end-of-life care (Anderson, Williams, Bost, & Barnard, 2008). This suggests that LTC home staff, having witnessed past deaths of residents, would have more knowledge about end-of-life issues and better attitudes towards providing end-of-life care, making them better able to care for this vulnerable population.

Although this research does not shed light on how staff communicated about end-of-life stages with residents, or if this was a reasonable thing to do, I can comment on the ability of staff to speak with and guide families through their loved one's end-of-life. Wadensten, Conden, Wahlund, and Murray (2007) argue that residents may need the opportunity to talk about death and it is therefore the duty of staff to listen and support them through these conversations. In this research, we can see that River Manor did an excellent job of being available and open to having these conversations with family members are also likely to need to have space to discuss these same issues. One tool that River Manor used to help families understand what happens during end-of-life was a facility-specific booklet on end-of-life experiences. The ability to offer this guidance demonstrates the possibilities of providing care throughout the end-of-life journey within the LTC system. Moreover, the ability of staff to discuss death and dying has been shown to instil trust and decrease stress and anxiety amongst family members (Stajduhar et al.,

2011). At River Manor, these institutional qualities enabled some family members to achieve a “good death.”

Advocating that Death is Natural Helps Families Cope

Within the literature, LTC homes are most often produced as waiting houses (Tuckett, 2007) or warehouses to store people until they die (Nolan et al., 1995). The care at River Manor stands in contrast to this literature. Not only were residents supported in living well and being meaningfully engaged when they were well, they were also supported and cared for when their health began to deteriorate. Death is not, and cannot, be ignored or hidden in this setting. Embracing death as natural enabled River Manor staff to support residents throughout their end-of-life journey. In this sense, families spoke highly of River Manor, citing its reputation within the community and how, both aesthetically and functionally, the home was comforting and a meaningful piece of the community.

As noted in my literature review, the physical design of LTC homes can pose many challenges for residents (Cooney, 2012). Having the option to use a palliative room or to support residents through their end-of-life journey in their own room, demonstrates River Manor’s ability to support residents in the home; rather than having them transferred to hospital. This is significant, because as Brazil et al. (2006) found, people often articulate a desire to die at their LTC home rather than move to a hospital. Conceptualizing LTC as a home, these findings align with the preference to die at home rather than in a facility or in an acute-care hospital at end-of-life (Wilson, 2000; Wilson, Cohen, Deliens, Hewitt, & Houttekier, 2013). At the same time, Vohra, Brazil, Hanna,

and Abelson (2004) found that compared to families who had a relative die in hospital, families were more satisfied with care when their relative died in a LTC home.

River Manor appears to be adept at skilfully communicating the death of a resident to other residents. In the past, staff at River Manor have placed a symbol on the door of a deceased resident or put pictures of them in the hall. Although all residents may not be comfortable with death (Crick, 2004), trying to protect people from confronting death is problematic (Katz et al., 2001). Not telling residents about someone's death within the LTC home can result in this information being passed "through the grapevine" and it can be hurtful not to be directly told that another resident has died, especially when there was a personal connection to other residents (Tan et al., 2013). River Manor appears to have addressed this paradox by using subtle signifiers, which also functions to signal a loss to the community.

Learning of the death of another resident can have different meanings to other resident in the home and the meaning residents find in the death of a fellow resident is often influenced by the relationship they had with that person (Djivire, Levin, Schinke, & Porter, 2012). Residents experience a family-like loss when they had a personal relationship with the person who died, and intentionally distance themselves from the death when they did not know the person or when their awareness of death becomes overwhelming (Djivire et al., 2012).

Beyond family members and other residents, staff can also experience grief after the death of a resident. The death of a resident was also a loss for the River Manor community. Despite their grief, however, staff must continue working (Chroinin et al., 2011). Hence, we should consider how to better support staff after the death of a resident

-- or we risk compromising their health and ability to sustain a high level of emotional care.

Residents at River Manor and their families witness the death of others in an open and natural way. Although none of my participants explicitly spoke of having witnessed the death of other residents in the home, I wonder what role having witnessed other deaths in the home may have impacted residents and their families. Anderson et al. (2008) found medical students who had been exposed to the death of a patient during medical school to have more positive attitudes towards end-of-life care than students who had not had that exposure. It is possible that because of the care and respect that families witnessed when other people had died at River Manor that they held more positive attitudes towards their relative's death and the care they were receiving during their end-of-life. Payne, Hillier, Langley-Evans, and Roberts (1996) suggest that witnessing a death can be reassuring and comforting to residents and they feel they will not be neglected when they die themselves. It stands to reason that families would also be comforted after witnessing another resident die with the LTC home to know that their loved one will be care for.

Although death may be accepted and viewed as natural at River Manor, the language surrounding that conversation is still tricky. Having struggled with whether "good death" was the best language to use in this research, I decided to ask participants to provide their opinion. Most participants were not fond of this wording; however, many did articulate an understanding of the rationale behind it. I then asked participants to suggest alternatives, but even those proved to be problematic. One participant, as an example, also noted that while she was fine with the phrase "good death," she was

concerned by its potential to limit our ability to talk about end-of-life experiences beyond a binary of good or bad. Instead, participants were better able to help sketch what constitutes a good death within LTC home setting. This included a compassionate approach to care, coming together to care, and the continuation of care.

In recent months, the Liberal government has worked to pass legislation in response to the Supreme Court ruling regarding physician assisted dying (Bill C-14, 2016; Lunn, 2016). As someone who has spent the past few years studying end-of-life care, I am excited about the emergence of a national conversation on death and dying. What constitutes a good death, and what that language represents has changed over time (Kehl, 2006) and it is possible that we are once again standing on the cusp of another historical shift. Moving forward, this shift gives me hope that Canadians will soon begin to have more honest conversations about end-of-life care in LTC homes. Borrowing from the existing model of hospice care to align the end-of-life practices in LTC homes with the existing practices of hospice care has the potential to have a significant impact on the lives of many Canadian families.

Care Beyond the Person

Although River Manor practices under a philosophy of person-centred care, the umbrella of care expanded to include family members at end-of-life. Indeed, the additional support offered to families throughout their loved one's end-of-life care and after their death could be argued as a family-centred approach to care. Family-centred care is built on partnerships between healthcare providers, family members, and patients (residents) that are beneficial to all parties involved (Institute for Patient and Family-Centered Care, 2010), which Boerner, Burack, Jopp and Mock (2015) consider to be part

of good end-of-life. One of the criticisms of person-centred care is that with the focus on individuality and autonomy it can neglect interdependence and relationships (McCormack, Roberts, Meyer, Morgan, & Boscart, 2012). By extending the care that staff provide to families, River Manor overcomes this challenge and provides an overall better care experience for families and their loved ones.

River Manor was able to provide meaningful care by developing connections and relationships with residents and their families. Stajduhar et al. (2011) note that families value behaviours that reflect a personal connection and my research supports these findings. Personal connections can be seen in River Manor's efforts to get to know individual residents and to engage them, when they were able, in activities that were personally meaningful, such as staff taking one participant's father to the gardens and making him a photo album of the gardens. Family members can be invaluable resources for staff to get to know residents, and understand their likes/dislikes their personal history, and their values (Boise & White, 2004). River Manor used families to better know and build a personal connection with residents.

Although I am sure staff at River Manor face many of the challenges noted in my literature review, such as heavy workloads (Sims-Gould et al., 2010), and time constraints, especially with the additional supports needed around end-of-life (Brazil et al., 2006; Katz et al., 2001), families had kind things to say about staff members at River Manor. Boise and White (2004) argue that having a welcoming facility environment is one way to engage families. Additionally, some of the ways that River Manor was able to support family members were not complex or required a lot of work on the part of staff, such as offering coffee or tea. Yet, these simple acts helped families feel supported and

feel that they and their family member were cared for and respected during this challenging time.

Although person-centred care and family-centred care are distinct models of care they also have overlapping and complementary elements (McCormack et al., 2012). I cannot help but wonder if when looking at the practical application of how we care within a LTC home if the label applied to the type of care is not that important. Rather, is the important thing that care is reflective of the humanistic emphasis that was central to the original ideas of person-centred care (McCormack et al., 2012)?

Memories of a “Good Death” are Relational

Within healthcare settings, clinical skills continue to be more highly valued than social skills (Armstrong, 2013). While clinical skills are easier to measure, for LTC staff, social skills are an essential part of the job. Administering a butterfly needle for pain management at end-of-life, for example, is a clinical skill. Being able to keep someone calm while administering the needle, however, is a social skill; as is supporting family members in understanding the need for this treatment. In my research, participants shared the emotional care (social skills) provided by staff at River Manor; perhaps, because families tend to expect physical care (clinical skills) in LTC homes (Munn & Zimmerman, 2006) or perhaps because the emotional care at River Manor went above and beyond their expectations. One of my favourite anecdotes from this research came from one couple describing staff making efforts to be as gentle as possible in rolling their mother/mother-in-law, and then tucking her stuffed cat back into her arms. This small act demonstrates tenderness and respect to residents and family.

Some participants chose not to use the palliative care room because it would have meant that their loved one would not have the same staff working with them because the palliative care room is located in a different area of River Manor. This speaks to the desire to continue to have staff working with residents who know them well. Munn and Zimmerman (2006) also note families desire to have consistent staff. There are many benefits to having the same staff work with residents including it being preferable to both residents and staff, and leading to better quality of care and quality of life for residents (Castle, 2011). When staff consistently work with the same residents, they have the opportunity to get to know them better and create connection with them, which better positions them to advocate for resident's preferences (Castle, 2011). Developing and fostering consistent and trusting relationships between staff and residents is an important component of person-centred care (Talerico et al., 2003). Finally, Forbes-Thompson and Gessert (2006) highlight problematic incidents of family members being treated poorly by LTC homes after the death of a relative, including a case where staff did not acknowledge a family member when she came to collect her loved one's things. In my research however, participants continued to receive exceptional emotional care after the death of their relative.

Implications and Recommendations

Through this research, I pursued a better understanding of end-of-life experiences in LTC homes from the perspective of family members who had a relative die at River Manor. In line with a Western medical model, LTC homes have traditionally focused solely on helping individuals live well. At River Manor, however, the existence of a specialized palliative care program calls attention to a recent shift within the LTC system.

Indeed, it appears that LTC homes are now beginning to seriously consider how to help individuals die ‘well’. In this research, the positive end-of-life experiences articulated by participants appear to stem from the way in which staff and management at River Manor respect both life and death. Moving forward, then, LTC homes looking to learn from the successes of River Manor could work to ensure that staff receive administrative-level support and training in relation to the three main categories discussed in this research (i.e. compassionate approach to care, coming together to care, continuation of care). Hence, this research has implications for both staff and administration at LTC homes.

Although we should not consider how we care for any population based on finances, particularly a population such as dying persons who, Wilson et al. (2008) argue to be some of the most vulnerable populations among us, I do think reflecting on the financial benefits of supporting people within the LTC home rather than transferring them to hospital is interesting. In an extensive study looking at the use and cost of a range of healthcare sectors in Ontario for people in their last year of life, Tanuseputro et al. (2015) outline how expensive the last year of life can be in terms of health-care. The average cost of a visit to the emergency room for people in their last year or life was found to be around \$1500, and inpatient care (without ICU) averaged over \$22000. Some hospital care may be important and valuable towards the end-of-life, but if more LTC homes can support residents within the LTC home, they may not only provide better care because of having consistent staff, being in a comfortable and familiar environment, they could also help to alleviate some of the strain on our healthcare budget.

In Western society, we are taught to avoid discussing issues related to end-of-life care. In this sense, perhaps the most unexpected finding from my research was my

participants' willingness to talk about their relatives' end-of-life journey. I did not expect such openness. I wondered what role their relatives' positive end-of-life experience at River Manor played in their willingness to talk about death and dying with me.

On a personal level, I now recognize the importance of communicating with my parents and grandparents about what they would like for their own end-of-life care. At the same time, however, I am still unsure of how best to begin this conversation. How do we talk to the people we love about their end-of-life journey -- especially when they have had negative experiences with LTC homes? Maybe I will place a copy of this thesis on their pillows for some late night reading. What role can LTC homes such as River Manor play in shifting the national conversation on death and dying?

This research adds to the growing body of literature surrounding issues of death and dying, specifically in LTC homes. It is important for LTC homes within Canada, and specifically Ontario, to be able to base their practices on research that takes place in the same context in which they are trying to enact change. This research helps to identify what contributes to good death within an Ontario community, which may not only support LTC staff and administration in improving the end-of-life experiences for their residents.

The framework of respecting life and death, and the aspects of care that contribute to this theme may offer a new perspective to the growing body of literature related to end-of-life care within LTC homes. Does a compassionate approach to care support residents and families at end-of-life in other LTC homes? Are there other ways that staff, families, and residents come together to care for one another and dying residents? Is River Manor unique in extending the care that they provide to families, even after the

death of their loved one? This research sheds light on these concepts within the setting of River Manor but leaves room for these ideas to be further explored by future researchers.

Although this research contributes to the body of knowledge of what it means to have a good death within a LTC home setting, as I step back from this study, I see the many questions still to be answered about end-of-life care within a LTC home setting. Staff at River Manor played a significant role in the experience of family members and their relatives within the LTC home. For staff to be able to support residents and their families, it is important that we understand what supports are currently in place and what supports need to be in place to enable staff to provide outstanding care for individuals as they approach the end of their lives. Crandall et al. (2007) argue that strong management and administrative support can play a major role in the success of programs. LTC staff and administration may provide important insights into the potentials and limitations of achieving a good death within the current system.

Although family members are commonly used as proxies in end-of-life research (Burge et al., 2014), it is also important that we explore these issues from the perspectives of residents within LTC homes. What constitutes a good death is individual (Payne et al., 1996) and varies from person to person and changes over time based on experience, situation, and role (Kehl, 2006). Mathie et al. (2012) remind us all that older adults are able to talk about living and dying when given the time and space to do so. Building relationships that help residents feel comfortable in having these conversations may be an important first step in learning what is most important to people in the later stages of their life. It is important that care staff and families are supportive of residents, but also recognize that asking residents about advanced care planning may not align with the

priorities of all residents; such as someone who is focused on living day-to-day (Mathie et al., 2012). Family members in my study felt well prepared for their loved one's death, but I am left wondering if their loved one was prepared. Were residents satisfied with the amount of information the home and their families had about how they would like to die? Did they know everything that they needed or wanted to know about what end-of-life care would look like at River Manor? Are end-of-life issues concerns that older adults living in LTC homes have?

Finally, I think that I am no closer to understanding the best language to use when talking about dying. Despite the significant amount of time that I have spent researching this topic, I still find myself struggling to know the best language to use to describe a "good death." What makes a good death is individual and dynamic (Kehl, 2006); perhaps this is where some of the challenge in finding the "right" language to use is derived. I am confident that it is possible for people to have positive end-of-life experiences, and that this is an important issue to explore. I would, however, encourage future researchers to carefully consider the language they use. Good death, dying well, and peaceful death are all examples of language that can be found within the literature and sometimes these terms are used interchangeably and sometimes they are used for different meanings (Kehl, 2006). It is important that we carefully consider and are clear about the meaning behind the language that we are using. I would also encourage future researchers to ask themselves if the people impacted by these experiences are comfortable with the terms used.

Conclusions

Every so often I am reminded that death is something that will happen to all of us. In this sense, I find it comforting to know that homes like River Manor exist and work to support residents and their families as they embark on this final journey. I would echo the sentiments of Goldsteen et al. (2006) and Steinhauser and Clipp (2000) who argue that care providers need to understand that a good death does not result in restricting what dying well looks like or formulating a right way to die. It is important that we recognize that what constitutes a good death varies by cultural background, experience, and other demographic characteristics such as age and gender (Schwartz et al., 2003). What is needed is a greater push towards a holistic care environment, with an increased focus on aging well, remaining active into late stages of life, and approaching care from a person-first perspective. In this context, it is my hope that my research can help to expedite the cultural shift that is occurring in LTC homes. No longer is it enough to focus on living and aging well. Indeed, if LTC homes are to support people in living well through the later and often final years of their lives; they also need to be prepared to support residents in dying well. In other words, care for the living must be extended to care for the dying.

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Appendix A: Letter of Invitation to Administrator

Dear [insert name here]:

I would like to invite you to participate in a study I am conducting in the Department of Recreation and Leisure Studies at Brock University. The purpose of this letter is to inform you of what participation in this study would entail, and ask for your consent to conduct my study at [insert name here].

This proposed research aims to understand the experience of death within a LTC home from the perspective of bereaved family members. I hope to conduct a set of 2 in-depth interviews with 5-7 individuals who had family members passed away while living in a LTC home. The ideal length of interviews is approximately one hour. Each interview will be scheduled at a date and time convenient to each participant. The focus of the interviews will be on how family members describe their experiences of end-of-life care, factors that enable and hinder the experience of dying and death in the LTC home and how family members perceive their role in supporting a relative during this time. After transcribing the interviews and conducting an initial analysis, I would like to meet individually with participants again to give them the opportunity to confirm the accuracy of our conversation, and to add or clarify any points. As well, I would like to use this time to share with them the initial findings and ask for their input and if they feel the results are representative of their experiences.

Participation in this study is completely voluntary. Participants can decline to answer any particular questions if they wish, and can withdraw from the study at any time by simply notifying me. In order to protect the anonymity of the LTC home and all participants as best possible, pseudonyms for the home and participants involved in the study will be used in all notes taken throughout the research and in written and oral reports of the research. No identifying information will be attached to descriptions of the LTC home or any of the participants.

All audio recordings collected during this study will be stored on a password-protected computer and hard copies of transcripts will be stored in a locked filing cabinet at Brock University. Upon completion of the study (December 2015), audio recordings and transcripts of the interviews will be destroyed.

At this time, I am seeking your consent to conduct my research at [insert name here]. Please know that this study will be reviewed through the Research Ethics Board (REB) at Brock University and you will be provided with the REB ethics approval for your records. Until my research has been successfully reviewed through the REB, I will not be soliciting anyone at [insert name here] to participate in my study.

If you have any questions, I would be more than happy to meet with you to further discuss my research. Please feel free to contact me by email <st08tg@brocku.ca> for more information.

Thank you for your assistance with this research. I look forward to hearing from you.
Shannon Thoms, Department of Recreation and Leisure Studies, Brock University

Appendix B: Declaration of Support for Administrator

I have read the information letter provided by Shannon Thoms, Department of Recreation and Leisure Studies at the Brock University, describing the purpose of her study.

My consent to [insert LTC home name here] participation in this research is made under the following conditions:

1. Participation is completely voluntary and all data collected will be used solely for research purposes.
2. All information will be kept strictly confidential, accessed only by Shannon and her faculty supervisor.
3. Pseudonyms for the LTC home and all participants involved will be used on all documents pertaining to the study and in all oral and written reports of the research.
4. Family members involved in the study may withdraw from the study at any time by simply informing Shannon, and may refuse to answer any questions during their interviews.
5. I may request an executive summary of the findings upon completion of the study. This will be available through Shannon at Brock University upon completion of the study.

I understand this study will be reviewed through the Research Ethics Board (REB) at Brock University before Colleen can conduct her research at [insert name of LTC home here].

Please accept this declaration of support for Shannon Thoms, to conduct her research [insert name here].

Signature of Administrator: _____ Date: _____

Signature of Researcher: _____ Date: _____

Appendix C: Information Letter for Participants

March 2015

The purpose of this letter is to ask if you would like to participate in a research study entitled: “Understanding End-of-life in a Long-Term Care Home: Perceptions of Bereaved Family” which seeks to understand the experience of dying and death in a long-term care home setting from the perspective of family members who have had a relative die in a long-term care home.

It is my hope that the findings of this study will enable me to better understand the experiences of family when a relative passes away within a long-term care home. Having a better understanding of what helps enable a person to achieve a good death could help long-term care homes to focus their efforts and engage in practices that are valued by family members when supporting people approaching the end-of-life.

Your participation in this study would involve:

- speaking with me about your experiences of when your family member passed away during one to two individual interviews. The ideal length of interviews is approximately 1 hour. Our conversations will be conducted at a time and place convenient for you. I am most interested in talking with you about how you describe your experiences of end-of-life care, what supports or hinders the experience of dying and death, and how you perceived your role in supporting your family member through this experience.

I would like to audiotape my conversation with you so I can better understand your personal experiences and have an accurate record of our conversation. All audio recordings collected during this study will be stored on a password-protected computer and hard copies of transcripts will be stored in a locked filing cabinet in my office at Brock University. Upon completion of the study (December 2015), audio recordings and transcripts of the interviews will be destroyed.

If you decide to take part in this study, I will be asking you to sign a letter formally stating consent to participate. Participation in this study is voluntary and you may choose not to participate. You may decline to answer any of the interview questions if you so wish. Further, you may decide to withdraw from this study at any time without any negative consequences by advising me. Information gathered throughout this study will be kept confidential and will only be accessed by myself and my faculty supervisor. Should you speak of other residents, family members, staff, and/or [insert name of LTC home here] during your interviews with me, the identities of these individuals and the home will remain confidential. Your name will not appear in any report resulting from this study, however, with your permission anonymous quotations may be used. Each participant of this study will receive an executive summary of my research findings in January 2016.

Once I have had a chance to transcribe and analyze the information I've collected from initial interviews, I would like to meet with you for a second interview. The purpose of this second interview is to give you the opportunity to confirm the accuracy of our conversation, and to add or clarify any points. As well, I would like to use this time to share with you the initial findings and ask for your input and if you feel the results are representative of your experiences.

This study has been reviewed and received ethics clearance through the Research Ethics Board (REB) at Brock University. However, the final decision about participation is yours. If you have any questions about your rights as a research participant, please contact the Brock University Research Ethics Board (905-688-5550 ext. 3035, reb@brocku.ca) and quote my REB file number (##-###).

Should you have any questions about my study, please contact:

- Shannon Thoms by email at st08tg@brocku.ca
- Dr. Colleen Whyte, faculty supervisor, at (905) 688-5550 ext. 3124 or by email at cwhyte@brocku.ca
- [name of contact at LTC home] would also be happy to answer any of your questions.

I very much look forward to speaking with you and thank you in advance for your assistance in this study.

Shannon Thoms
Department of Recreation and Leisure Studies, Brock University

Appendix D: Consent Form

I have read the information presented in the information letter about a study being conducted by Shannon Thoms of the Department of Recreation and Leisure Studies at Brock University. I have had the opportunity to ask any questions related to this study and have received satisfactory answers to my questions.

I am aware that I have the option of allowing my conversation to be audio recorded to ensure an accurate recording of my responses.

I am also aware that excerpts from our conversation may be included in the publications to come from this research, with the understanding that the quotations will be anonymous. I have been informed that participants may withdraw their consent at any time without penalty by advising the researcher.

This study has been reviewed by, and received ethics clearance through the Research Ethics Board at Brock University. I have been informed that if I have any comments or concerns resulting from participation in this study, I may contact the Brock University Research Ethics Board (905-688-5550 ext. 3035, reb@brocku.ca).

With full knowledge of all foregoing, I agree, of my own free will, to participate in this study.

☐ YES ☐ NO

I agree to have my conversation audio-recorded.

☐ YES ☐ NO

I agree to the use of anonymous quotations in any publication that comes of this research.

☐ YES ☐ NO

Participant
Name: _____

Participant
Signature: _____

Witness
Name: _____

Witness
Signature: _____

Date: _____

Appendix E: Conversational Guide

1. Tell me about your family member. (Probe: What was your relationship to this person?)
2. Can you tell me a bit about their experience of living here? What was your experience of visiting him/her in the LTC home?

Research Question 1: How do family members describe their experiences of end-of-life care in LTC?

3. As I've mentioned, my research is about understanding ways in which LTC homes support residents as they approach the end-of-life. The term used is "good death." What does a good death mean to you? (Probe: How did this LTC home honour these aspects/support you with those things?)

Research Question 2: What are the organizational practices that contribute to and hinder the experience of dying and death within a LTC home?

4. Thinking about your experiences leading up to the death of your family member, what stands out to you as contributing to him/her being able to achieve a good death?
5. Thinking about your experiences leading up to their death, what stands out to you as having hindered the experience?
6. Can you describe some of the tangible actions staff engaged in to support you and your family member at his/her end-of-life? (Probe: How did staff interact with your loved one? How did they involve him/her in decision-making? How did they involve you in decision-making?)
7. How did the home/staff support you before his/her death? At the point of death? Did you receive any support after his/her death?
8. Can you talk about the space of this LTC home and how it felt to be here during this emotional time?

Research Question 3: How do family members perceive their role in supporting a relative during the end-of-life?

9. How willing were staff members to involve you in his/her care? (Probe: What role did you play in the care of your family member leading up to his/her end-of-life?)
10. How has the experience of a good death helped you in working through your own grief?
11. Is there anything we didn't talk about that you would like to add?